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Caregiver Burden: A Qualitative Approach to Understanding the Experiences of Caregivers to Technologically-Dependent Children with Cerebral Palsy

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CAREGIVER BURDEN:

A QUALITATIVE APPROACH TO UNDERSTANDING THE EXPERIENCES OF CAREGIVERS TO TECHNOLOGICALLY-DEPENDENT CHILDREN WITH CEREBRAL PALSY

by

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ABSTRACT

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Cerebral palsy (CP) is a broad term that refers to a group of chronic neurological disorders that impairs motor functioning due to damage to a developing brain. Caring for a child with CP who is technologically-dependent is a challenging experience. The caregiver's experiences are critical to understanding this population and learning best how to serve its needs. Therefore, this thesis qualitatively explores both the burdens and benefits associated with caregiving for a child with CP.

The findings from such exploration suggest that two types of burden, objective and subjective, are present in the lives of these caregivers, as well as benefits received from the child or the caregiving situation. Furthermore, evidence suggests these two types of burdens are often intertwined and when compounded, it can make certain individuals more burdened than others.

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Chapter 1

Introduction

"There are four kinds of people in the world: Those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers."

Rosalynn Carter, Former First Lady

Cerebral Palsy in the United States

Currently, there are approximately 5.9 million children living at home with a severe disability in the United States (Manuel, Naughton, Balkrishnan, Smith, & Koman, 2003). In 1992, the prevalence of cerebral palsy (CP) was 2.3 per every 1,000 live births in the United States, and is one of the most common conditions leading to disability affecting children (Glasscock, 2000; Manuel et al., 2003; Perrin, 2002; Petersen, Kedia, Davis, Newman, & Temple, 2006). According to the CDC (2010), the current average prevalence of CP is 3.3 per 1,000 among 8-year-old children or 1 in 303 children, and each year about 10,000 babies born in the United States will develop CP. This report concluded that the prevalence was higher among boys, and the most common form was spastic CP, which is also the most severe. For all those born in 2000 with CP, the cumulative estimated lifetime cost of care is $11.5 billion (CDC, 2010).

CP is the leading cause of severe disability in childhood in this country (CDC, 2010). CP is an "umbrella" diagnosis, meaning that causes, types, and results are very different for every child and no two children experience CP in the same way (National Institutes of Neurological Disorders and Stroke [NINDS], 2010). Many children who are severely disabled can have a CP diagnosis.

However, not all children who have CP are severely disabled. They may walk with a limp or braces, but function more similarly to a typically developing child, than do children who have severe CP and require technological assistance. This thesis is specifically concerned with those who are more severely affected and dependent on technologies. The objective of the study is to understand the burdens and benefits associated with caregiving to a technologically-dependent child.

What is Cerebral Palsy?

According to the National Institute of Neurological Disorders and Stroke (2010), CP is a disorder of movement, tone, and posture. A person with CP has static brain damage that affects or limits their ability to control their muscles, sometimes severely limiting their ability to move their bodies. As mentioned, CP is a non-progressive brain injury; however symptoms and outcomes of CP do change and potentially can become worse as the child grows. There are four types of brain injuries that give rise to CP: (1.) Damage to the white matter of the brain; causes include genetic, viral, or environmental, such as prenatal exposure to toxic substances, child abuse, or improper use of a car restraint that results in damage to the white matter of the brain. (2.) Abnormal development of the brain; causes include viral or genetic. (3.) Bleeding in the brain; causes include environmental, such as maternal or child abuse that results in a brain bleed, and random internal occurrences such as a stroke. (4.) Brain damage caused by a lack of oxygen in the brain; causes include birth trauma or placental rupture (NINDS, 2010). All of these types can be seen on a Magnetic Resonance Imaging (MRI).

Occasionally, a diagnosis of CP is made despite no abnormalities evident on an MRI. Severe cases of CP are usually evidenced by abnormalities on an MRI and an electroencephalography (EEG) as many children may have comorbid seizure disorders (NINDS, 2010).

Acquisition of CP. One may either have congenital or acquired CP. Most affected children are born with congenital CP, as it stems from a prenatal or birth insult, that results in one of the four types of brain injuries. Some congenital causes include a pregnant mother contracting cytomegalovirus, having certain genetic conditions, or a fetus having a stroke in-utero. As many as 90% of CP cases have unknown etiology and are assumed to be congenital in nature (NINDS, 2010). Another example of congenital CP includes asphyxia during the birth process, which is estimated to only account for 5 to 10% of all CP cases (NINDS, 2010).

A small percent of children have acquired CP, which occurs from a postnatal insult (NINDS, 2010). Several medical conditions cause postnatal CP, including meningitis, viral encephalitis, severe jaundice, and stroke (CDC, 2010; NINDS, 2010). Some forms of acquired CP can be prevented. Environmental factors that can result in CP, which are preventable, include child abuse and motor vehicle accidents, which result in permanent brain damage. The environmental causes can be prevented through abuse awareness and education of the proper use of child restraints (CDC, 2010).

Types of CP. The nature of brain damage can result in different types of CP with varying degrees of severity. The main types of CP are spastic hemiplegia, spastic diplegia, spastic quadriplegia, dyskinetic, and ataxic cerebral palsy.

These categories are further delineated below. Of note, there is another category called mixed CP, which indicates that a person is afflicted by more than one type at the same time, usually representing one of the most severe manifestations of CP (NINDS, 2010).

1. Spastic hemiplegia usually affects the arm, hand, and leg on one side of the body. Children with this type walk later and on their tip-toes, because of tight heel tendons, which can be released by surgery, greatly reducing their affectedness. Their intelligence is usually in the normal range; however they may have speech delays and impairments.
2. Spastic diplegia is characterized by muscle stiffness predominantly in the legs and less severely affects the arms and face, although the hands may be clumsy. Children with this kind of CP may require a walker or leg braces. Intelligence and language skills are generally normal.
3. Spastic quadriplegia is the most severe form of CP, and often is accompanied with moderate to severe mental retardation. This form is caused by widespread damage to the brain or significant brain malformations. Children will often have severe stiffness in their limbs but a floppy neck or trunk. They are rarely able to walk. Speaking and being understood are difficult. Seizures can be frequent and hard to control.
4. Dyskinetic CP is characterized by slow and uncontrollable writhing movements of the hands, feet, arms, or legs. In some children, hyperactivity in the muscles of the face and tongue makes them grimace or drool. Intelligence is rarely affected in these forms of cerebral palsy.

5. Ataxic cerebral palsy is a very rare form of CP that affects balance and depth perception. Children will often have poor coordination and will walk unsteadily with a wide-based gait, placing their feet unusually far apart. (NINDS, 2010)

Co-morbid Conditions. Usually, children with a more severe form of CP will have at least one co-morbid condition. Some of the most common conditions are mental retardation; seizure disorders; delayed growth and development; spinal deformities; impaired vision, hearing, or speech; drooling; incontinence; and abnormal sensations and perceptions (NINDS, 2010). A person is more likely to have both a mental impairment and seizures if they have an abnormal EEG or MRI, and as many as 20-40% of people with mental retardation and CP have seizures (NINDS, 2010). These additional medical problems translate to a pronounced challenge of caring for a child with CP, particularity one who is technologically-dependent. According to the Office of Technology Assessment, the term technologically-dependent refers to medical technology that compensates for the loss of normal vital body function and that requires substantial daily skilled nursing care to avert death or further disability (US congress-cited in Leonard, Brust, & Sapienza, 1992). Examples of medical technology are a ventilator, intravenous therapy, and nutritional support. The most common technological assistance for those with CP is nutritional support via a G-tube and to eliminate respiratory problems through a tracheotomy (trach) (Montagnino and Mauricio, 2004).

The Nature of Severe Cerebral Palsy. The effects of CP can target any muscle group in the body. Therefore, as a child with CP grows so too does the impact on the body and muscle groups.

This can result in older children with CP developing scoliosis or a permanent contraction; their hands or feet may become permanently stuck in an unnatural fixed position. Many children as they age need to increase caloric intake, and they may require the use of a gastronomy tube (G-tube). Additionally, many children have seizures, which can cause long-term brain damage, and this may be especially evident as the child ages (CDC, 2010). Cerebral palsy cannot be cured. However, depending on the severity of effects on muscle groups, there are treatments that can help reduce the effects on the body. Some of these include physical therapy, occupational therapy, pharmacotherapy, surgery, and orthopedic braces (CDC, 2010). All of these techniques require extra time on the part of the caregiver, and overall can increase the amount of care needed for these children.

Of more concern, is the impact that CP has on the most essential activities of daily living. Hygiene can be equally challenging. Bathing aids are needed to position the severely disabled child in order to clean him or her. Additionally many bathrooms do not have large enough tub spaces or hanging showerhead that reach a child in a positioning aid, which further complicates bathing and increases financial burden to the families to accommodate such adaptations. Drooling can also be a problem for hygiene. Diapering can become difficult as the child reaches puberty, becomes too large for changing tables, and as their muscles become stiffer particularly in the hips and legs. Children can also grind and break their teeth, as they may not be able to control the muscles in their jaws. This can be painful for the child and caregiver alike.

Child Survival and Technology

Technological advances in medical care of neonatal and pediatric health have increased survival among children with CP. This has increased the number of children living who are chronically ill, disabled, or technologically-dependent (Kuster & Badr, 2006; Montagnino & Mauricio, 2004).

Technology. For the purposes of this thesis, technological-dependence of a child will be used in reference to a child who has either a G-tube or a trach. A G-tube procedure refers to the placement of a tube from the epidermis through the abdominal wall into the stomach. This can ensure adequate nutrition for a child who has difficulty swallowing or aspirates on food (Davidson, Catto-Smith, & Beasley, 1995; Petersen et al., 2006; Spalding & McKeveer, 1998).

Placement of a G-tube usually occurs after all other means have been explored, because of complications that may arise (Brant & Ferrari, 1999). Negative consequences of G-tubes include leaking from the site, infections, skin integrity problems, need for its replacement as the child grows, tube blockages, deflation of the balloon that holds the tube in the body, restrictions on movement by the child, and problems with who can legally feed the child (Montagnino & Mauricio, 2004; Spalding & McKeever, 1998). According to the National Heart, Lung, and Blood Institute (2010), a tracheotomy is a surgical procedure that makes a hole into the front of the neck through the trachea. A trach provides air that can bypass the nose and mouth via the tube being located directly into the windpipe. Although the procedure itself is relatively safe, serious complications include bleeding at the site, infections, and clogging. There are often additional complications if the trach is attached to a ventilator.

Proper care of the trach and the tracheotomy site can eliminate many of the problems, yet appropriate diligence requires full-time supervision, including night-time care in many situations. Many children with a trach also have a G-tube (Montagnino & Mauricio, 2004).

History of Home Care for the Chronically Ill and Severely Disabled

During the early nineteenth century, caring for the ill was done in the home with the aid of house calls by doctors and nurses. Hospitals were a last resort for many families (Buhler-Wilkerson, 2007). Often it was the indigent that required the most attention of in-home care providers, and were cared for by wealthy women's groups, who viewed the care they provided as charity (Buhler-Wilkerson, 2007). At the same time, the groups who cared for the chronically ill were concerned about the financial impact and the time needed to care for the poor and disabled. By the early part of the twentieth century, these women's groups had evolved into nursing organizations supplemented by Metropolitan Life Insurance Company (MLC), which was marketed towards the working class. By 1910, 20% of the U.S. population held MLC insurance policies (Buhler-Wilkerson, 2007). This created a dramatic paradigm shift in the management of home health care, because as the number of policy-holders grew so too did the amount of expenditures. MLC was a for-profit business, and the amount of payout reduced the company's profits. A large portion of the expense was spent on caring for chronically ill care cases. The MLC implemented new management techniques that focused on acute care, mostly obstetrical procedures, and eliminated non-profitable services, i.e. chronically ill patients.

Over the next 40 years, popular thought concerning where to house the chronically ill changed between complete in-home nursing care, custodial homes, outpatient clinics, and informal home care (Buhler-Wilkerson, 2007).

By the 1960s, Medicare legislation affecting the elderly and medically-needy resulted in government-sponsored home care becoming the norm. The government offered an array of services under these new laws, yet these laws presupposed that families could and would be able to care for their aged parents or other family members, many of whom qualified as disabled and chronically ill. Many physicians were concerned with this type of home care design, because it limited access to the aged with and without chronic illness (Buhler-Wilkerson, 2007). Simultaneously, Medicaid, which was created to help the poor, did pay for both institutional and home-based long-term care (Fox, 1993; Stevens & Stevens, 1974; Vladeck, 1980). Many elderly people were concurrently eligible for Medicaid and Medicare, and families noticed the difference in the long-term health care policies of each insurance plan. Therefore, many families enrolled their dependent in Medicaid and chose to place them in non-home based care, like nursing homes. Medicaid began to share some of the financial burden of Medicare, and institutionalization became common for the elderly as well for the younger chronically ill, including children.

In 1999, the Olmstead Act was passed, which mandated community alternatives to the institutionalization for the disabled and mentally ill. Once again, home-care for the chronically ill and disabled became the most cost-effective option and a socially acceptable practice (Buhler-Wilkerson, 2007).

While the Olmsted Act responded to many abuses occurring in nursing homes, there was little attention paid to implementing family and community awareness and education campaigns to help these institutionalized individuals assimilate into society. Additionally, there were no support services or financial assistance programs implemented for family members to help them adjust to having a disabled adult or child in their homes. This move resulted in many positive outcomes for the patients, but the motivation was primarily financial cost reduction. The push toward home care for children who are technologically-dependent was based on rising hospital costs, reduced reimbursement by payers, and the acknowledgment of detrimental effects of prolonged institutionalization on normal child development and the family unit (Quint, Chesterman, Crain, Winkleby, & Boyce, 1990). Almost 20 years later, there still is little understanding of how these families function in the society at large. Therefore an understanding of these caregivers' burdens, both objective and subjective burdens, will add a level of understanding that tackles some of these problems with a holistic view of the personal, financial, familial, and societal cost associated with caregiving of these children.

Insurance. It seems fitting to address the current insurance issues involved with severely disabled children and technological dependencies, as many of the financial issues can be attributed to a lack of appropriate insurance coverage (Buhler-Wilkerson, 2007; Leonard et al., 1992). For technologically-dependent children with CP, private insurance can only be acquired through a parent's job, because at present, these children are considered uninsurable in the private sector due to major preexisting conditions. However, with the Health Care Reform Bill of 2010, preexisting conditions will no longer be a reason for exclusion. This could dramatically change the way severely

disabled children are insured. Insurance problems with this population are significant, as 10% of children with severe chronic conditions utilize 70% to 80% of children's health expenditures (Szilagyi, 2003).

Private insurance requires premiums, co-pays, and out of pocket expenses once an individual reaches the cap, which can easily happen with a severely disabled child. Some companies do not pay for the child's non-medical necessities, such as the actual G-tubes, special diets, like those for a G-tube, connector pieces for the G-tubes, syringes for feeding, or diapers when the child grows too large for standard infant/child diapers (Leonard et al., 1992). Also, they may not pay for certain medical sub-specialties the children require (Szilagyi, 2003).

Public insurance can reduce some financial burdens while creating new ones. Public insurance for this population include Medicare, Medicaid, or State Children's Health Insurance Programs, S-CHIP. All these programs are federal programs, although states are able to make their own eligibility requirements. This can be problematic, because some states are much more generous when it comes to family income limits, while others require near or below poverty status to obtain coverage. Severely disabled children are eligible for Medicare because of their disability alone, yet must still meet financial limits. In addition, some states require that they receive Social Security Income payment, which also has its own income restrictions, in order to receive the Medicare coverage.

Medicaid also has income restrictions; however the major difference from Medicare is that all qualifying members of the family get insurance coverage once approved. These eligibility restrictions change frequently and are state specific making a situation very difficult and time consuming for parents to navigate.

State Children's Health Insurance programs usually have an income cap, although it tends to be much higher than other state and federal insurance programs. They also have a non-insured waiting period, and out of pocket expenses. The waiting periods required by these programs can be detrimental to this population, as continuity of care often predicts more favorable outcomes in a medically needy child (Szilagyi, 2003).

Overall, public insurance systems alleviate many financial concerns and can work better with families of children with severe disabilities; yet it can be difficult to meet the income restrictions (Szilagyi, 2003). Many parents of severely disabled children do not qualify for Medicaid, Medicare, or S-CHIP due to income restrictions, and miss out on health insurance coverage; durable medical equipment, such as braces, wheelchairs, bathing chairs, body lifts, and liquid formula for feeding via G-tube, no out of pocket medical and pharmacological expenses, and continuity of care.

Caregiving for a Child with Severe Disability. In 1997, an estimated 25.8 million caregivers, both to children and adults, provided about 24 million hours of care with an economic value totaling $196 billion (Arno, Levine, & Memmott, 1999; Wagner, 2004). More recent estimates place the value of unpaid caregiving to be closer to $257 billion (Gould, 2004). In 2010, approximately 65.7 million informal caregivers provided 80% - 90% of the long-term assistance in the home to children and adults with physical or cognitive limitations (Rosalyn Carter Institute for Caregiving, 2010).

With rising numbers of child survivors of illness and accident, caregivers' needs and caregiving support systems will likely be a focal point for public health.

There is no agreed upon term for "caregiver". In this study, two types of caregiving will be referenced; informal and formal. An informal caregiver is typically an adult family member, usually a mother, who is unpaid and provides most of the care for a child who cannot care for themselves. Formal caregiving is generally when a non-family member, such as respite workers or institutional employees, comes into a home or institution, and receives payment for caring for a person who cannot care for themselves (Rosalyn Carter Institute for Caregiving, 2010). For the purposes of this thesis, the focus will be on informal or family caregiving and will be referred to as simply caregiving, unless otherwise specified.

Caregiving has a variety of effects on the person giving care. Not all effects are negative, as caregiving for a child with a disability can be as fulfilling as caring for a child without one (Ambert, 1992; King, Scollon, Ramsey, & Williams, 2000; Wilgosh, Nota, Scorgie, & Salvatore, 2004). Understanding the experiences of caregiving for a child with a severe disability can be divided, therefore, into two main categories; the negatives and positives.

Negatives Experiences Associated with Caregiving. Research suggests there is a greater need of support for families during transitional times after a child is diagnosed with CP. Specifically, Rentinck, Ketelaar, Jongmans, and Gorter (2006) conducted a meta-analysis on the adaptive process of mothers with children with CP and describe two situations when a child is diagnosed with CP where parents need transitional support:

first, when the child is not developing typically and the idea that their lives will present ongoing struggles; and second, when parents try to help their child develop as normally as possible, even though their help may not change the course of their child's condition.

Ones, Yilmaz, Cetinkaya, and Caglar (2005) assessed the quality of life and psychological status of mothers with children who have CP. The authors acknowledged the transitional needs of caregivers, and go further to say that caregivers, particularly mothers need more specific services, as their own social needs are often not met as they face challenges related to their child. Similarly, Meleski (2002) studied families with chronically ill children and noted that there are six additional areas of transitional need: initial diagnosis; when symptoms increase; when the child moves to a new setting such as a hospital; during a parent's absence, as in a divorce or military deployment, and during periods of developmental change.

Manuel et al. (2003) studied stress and adaptation in mothers of children with CP, through the use of surveys at a private orthopedic clinic. Of the 270 mothers, they found that 30% scored just above the cut-off for a diagnosis of clinical depression. Furthermore, severity and functionality of the child did not predict maternal depression. Depression was associated with the caregiver's perceived social supports. This was also the case for Kuster and Badr (2006), who explored caregivers with children on ventilator assistance living in the home, and found that social support was a significant predictor of depression. In addition, the overall impact of the caregiving situation on the family was related to depression in mothers/caregivers. Forty-five percent of their subjects reported depression. Also, they found that the number and length of hospitalizations were correlated with a greater depression score among the caregivers.

Moreover, they noted that within their population having a social support system became a protective mechanism by moderating the feeling of being overwhelmed. Social support is an important component in addressing emotional burdens related to caring for a child with severe disability. Montagnino and Mauricio (2004) found that caring for a technologically-dependent child created a greater sense of social isolation because the caregivers could not as easily move with the child, creating stress and anxiety in the caregiver.

Rentinck et al. (2006) reported that social network size and satisfaction with social support positively related to maternal mental health, and the physical limitation and behavioral problems of the child were related to greater physical stress in mothers. They also found that most studies they examined reported that mothers had higher rates of mental and physical stress and poorer mental health than mothers of typically developing children. Of interest, these authors noted differences in the caregiving styles and consequences for mothers versus fathers. Mothers tended to seek comfort and advice from others, while fathers kept problems to themselves. They also noted that mothers experienced more personal emotional burden and were more emotionally involved than fathers. The gender differences are important to look at as they may be implicated in experiencing of the positive and negative aspects of caregiving.

Both Brehaut et al. (2004), who studied primary caregivers of children with CP in Canada, and Kuster and Badr (2006) found that caregivers of children with CP had poorer health on a variety of physical and psychological health measures than any other groups of caregivers to children with disabilities.

They noted that CP caregivers were more likely to report a chronic stress condition, such as back problems, ulcers, and migraines as well as depressive symptoms than were caregivers to typically developing children.

Positives Experiences Associated with Caregiving. This notion of positive attribution associated with caregiving to a technologically-dependent child with severe disabilities is not well represented in the literature (Glasscock, 2000; Resch et al., 2010). Therefore, researchers in this area call for attention to comprehensively examine this phenomenon in relation to understanding the holistic psychological toll caregiving has on the caregiver.

Montagnino and Mauricio (2004) found that families of children with tracheotomies and G-tubes had less negative impacts overall on the caregivers than did families with children with myelomeningocele, children with brain injuries, and children with very low birth weight. They postulated that the skills learned by various technological interventions contributed to feelings of accomplishment in the caregiver to a technologically-dependent child. This reduced some of the negative feelings associated with caring for this type of child.

Glassock (2000) studied the phenomenological experiences of being a mother of a child with spastic CP. While all mothers reported significant caregiving stressors, such as time required to care and difficulty in caring, however they all reported strong family relationship and receiving help and support when needed. Mothers also reported a positive perception of the caregiving role, and all enjoyed mothering their child with CP.

Murphy, Christian, Caplin, and Young (2006) examined the health of caregivers of children with developmental disabilities in Utah.

The intent of the research was to explore caregivers' feelings about their current emotional and physical health as well as identify any factors that impaired or promoted their health. Of 40 caregivers studied, 30 children needed some degree of assistance with transfers, and 37 children required moderate to complete assistance with self-care tasks and communication, placing them in the severely disabled category. Several parents reported a positive and lasting impact on the whole family, including the caregiver. They felt like they had become more compassionate and more accepting to people with differences, some even mentioned that their child had influenced them to pursue healthcare careers. Also, they mentioned that being able to rise to the occasion with a child with additional needs gave them a greater purpose in life, hence increasing their positive attribution of taking care of a child with disabilities. The authors concluded that these positive outcomes can offset the negative implications of caregiving within the population.

A recent article by Resch et al. (2010) examined specific sources of challenges as identified by parents of children with disabilities. Authors used focus groups to examine the specific source of challenges as expressed by the parents themselves related to raising a child with a severe mental or physical disability. The authors reported many positive experiences of caregiving for a child with a severe disability. They found that caregivers raising children with disabilities often have a greater appreciation for life, greater spirituality, increased compassion and tolerance for people with disabilities, a more united family, and overall greater mental and emotional strength.

The authors also noted that despite the fact that their focus group questions were only designed to assess the needs and challenges of the caregiving experience, parents still volunteered the positive experiences they had. This observation further suggests the duality of consequences faced by caregivers. Authors make the distinction that the positive gain from the child and experience of parenting is not as a coping mechanism, but rather as a result of being a parent, particularly of a child with a disability. The experience promoted positive growth, which allows the caregiver and family to receive benefit from raising a severely disabled child (Resch et al., 2002).

Socio-cultural and Environmental Factors Affecting Severely Disabled Children

Adherence to Medical Regimen. Treatment of severely disabled children is prescribed by the medical profession; therefore regimen adherence among caregivers can be important. The assumption is that non-adherence to the advice will result in negative consequences in child's health; therefore adherence needs to be followed as directed, regardless of burden placed on the caregiver. Yet, adherence to complicated regimes can become problematic for caregivers, and can affect a caregiver's psychological mental health (Kuster & Badr, 2006). Though adherence problems among caregivers to children with trachs are not as evident in the literature, compliance has been shown to be difficult for caregivers of children with G-tubes (Petersen et al., 2006).

Spalding and McKeever (1998) qualitatively explored mother's experiences of feeding children with severe disability who require a G-tube describing how events leading up to G-tube placement can result in a caregiver's resistance towards its use.

In their study, most respondents reported feeding problems very early on in the child's life, and though these feeding problems were a source of concern for the caregivers, they often were not taken seriously by treatment providers. Mothers recalled that they had enormous difficulties convincing the doctors of these serious problems, and some doctors blamed the mother for their inexperience or over-concern. Only one of eight mothers initially consented to the G-tube insertion when it was first offered, despite the fact that almost all reported enormous amounts of time trying to feed their child. Allowing the child to receive a G-tube created a failure in the mother's mind, because they had 'given in' to the placement of the G-tube. Also, feeding the child through the G-tube created dissatisfaction among mothers, primarily because they were not able to feed the child through the mouth anymore. Moreover, they began to see themselves as experts on feeding their child, and many did not seek advice from medical professionals. Some questioned the nutritional value of the liquid food recommended for the G-tube. Many reported directly going against medical advice to feed their children a pureed diet through the tube. Many mothers attributed the improvement in their child's mental and physical health of their child to the G-tube diet change. Also, most mothers continued to feed their child through the mouth, as part of an attempt to prove the medical community wrong about the tube's placement as permanent.

Petersen et al. (2006) examined why caregivers continue to orally feed a child who had a G-tube. They reported that the permanency of the disability, stigma associated with G-tube feeding, the child missing the nurturing and pleasurable experiences of orally consumed food, and a lack of mealtime association were reasons given by caregivers for a lack of adherence.

Authors found that conflict between the medical community and the mother, social stigmas, cultural preferences about feeding, and the permanency of the child's disability seem to be directly related to whether a caregiver will follow medical advice. The suggested clinical implications were that the medical community should recognize these social and cultural notions held by parents, and they should focus heavily on the safety of the child when communicating adherence issues to the caregivers. Including people who can adequately assess the child's swallowing abilities and nutritional needs, such as a speech therapist and nutritionist, would make mothers seemingly more invested and offer a more comprehensive approach to feeding issues. This would reduce the harmful effects of oral feedings and increase the production of patient tailored adherence plans.

Transportation. Many children with severe physical disabilities have muscle tone problems, which can create difficulties with how they sit in a car and elsewhere. Hip dysplasia, or a dislocated hip, and scoliosis are common and can make sitting in a standard car seat difficult. There are car seats that are designed for children with orthopedic complications, yet they are very expensive, and the expense can be prohibitive for most families. If a child can even get into a standard car seat, the next problem is that most typical car seats have weight limits of 40 lbs and often have height restrictions. This inevitably creates a problem when a child grows both in weight and height. Practically, parents of children with CP have more back pain than parents of typically developing children, because moving a child who is physically impaired requires strength on the part of the caregiver (Brehaut et al., 2010).

For the severely disabled child, booster seats, which can safely hold children up to 100-150 lbs, are not options, because many of the children cannot sit unsupported, and need seats designed with five point harnesses for support. Additionally, many children are in wheelchairs, especially if they are older. For these children the use of handicap accessible vans is needed, which can create unmanageable financial costs.

Additional transportation problems include frequent feeding schedules and moving life-saving equipment. Planning is essential for moving a child with a G-tube, because children either are fed on schedules or are continuously fed using an electronic pump. There can be increased risk of vomiting if the child is moved too soon after feeding, and many caregivers must wait before moving their child (Yantzi, Rosenberg, & McKeever, 2006). As mentioned previously, a trach can present additional problems due to the nature of the device and the risk of dying without oxygen. Moving a child with a trach is complicated and is often a barrier for transportation. Moreover, the inability to easily move a child is a significant predictor of maternal feelings of isolation, contributing to a greater sense of depression in caregivers (Yantzi et al., 2006).

Financial Impact. It is estimated that 40% of families of children with special health care needs experience a financial burden due to their child's condition, and that families with a child with a severe disability have greater economic burdens (Anderson, Dumont, Jacobs, & Azzaria, 2007). Jacobs and McDermott (1989) studied the economic costs imposed on families with chronically ill and handicapped children. They reported a phenomenon called incremental cost, which refers to the economic burden related to caregiving functions in addition to the cost that would have been incurred in the absence of the child's condition.

Family caregiver costs were divided into four categories: direct or out-of-pocket home expenses on recurrent items, such as adaptive aid for toileting or bathing; direct travel expenses, such as gas and maintenance; the cost of durable medical equipment, like wheelchairs, braces, or feeding pumps, and handicap accessible home renovations; and the indirect costs of transportation and caregiving. The out of pocket expenses for a family of a child with severe disabilities are two to three times higher than those of a typical child (Anderson et al., 2007; Leonard et al., 1992).

Also, out of pocket expenses due to a limitation of private insurance companies can be significant sources of economic burden, as those expenses can easily cause distress among families with disabled children (Szilagyi, 2003). Technologically-dependent children have chronic needs of costly services, such as surgeries or monitoring of trach or G-tube sites, which inevitably increase medical travel costs and increase caregiver responsibilities (Szilagyi, 2003). Further, the question of institutionalizing or placing a child in foster care is directly related to whether the family can afford to care for the child in the home. If a non-home placement is chosen, this increases the cost for society. It has been recommended that providing some financial support for family home caregivers to help eliminate unnecessary and expensive long term institutionalization (Jacob & McDermott, 1989).

Respite Care. Respite care is when a formal caregiver comes into the home to care for an individual for a specified period of time in exchange for a set fee. Though it functions as an effective way to relieve primary caregivers, it can also create stress. Waiting lists for respite care, age restrictions for children, and under qualified respite workers are some of the issues by which this service can be compromised.

Also, the fluid nature of working with a respite company or government agency that provides care can mean that a family may receive one worker and then the next time a new one. This reduces the trust and ability of the caregiver to leave the child with the person because of a lack of continuity (Murphy et al., 2006; Yantzi et al., 2006). Respite care is intended to relieve caregivers so that they can engage in positive, recreational activities for themselves, including maintaining caregiver health and well-being; yet caregivers often find themselves completing chores that they cannot do with the child. An example was that a mother went to the grocery store during this time, because they cannot go there with the child, hence removing the 'restorative' time of the respite worker (Murphy et al., 2006).

Study Aims

The goal of this thesis is to examine the cumulative experiences of caregiving for a technologically-dependent child with CP, as evidenced by reporting both negative and positive aspects of the experience. More specifically, I will qualitatively investigate objective and subjective burden and identify the benefits of caregiving, referred to as positives with data obtained by 26 caregivers of technologically-dependent children with CP. Examining both objective and subjective burdens as well as the positive aspects of caregiving will help safeguard and respect the holistic nature of caregiving within this population.

Burdens related to Caregiving for a Child with CP. Caregiver burden is a concept that is interrelated and intertwined with the physical and psychological effects on the caregiver.

Burden is often interchangeable with distress, as distress is an outcome of caregiver strain that is a risk factor for caregivers' psychological stress, depression, or anxiety (Brannan & Helfinger, 2002; Canning, Harris, & Kelleher, 1996). For the purposes of this study, burden refers to the "perception that the caregiving situation exceeds the caregiver's resources" (Resch et al., 2010). Moreover, burden can be divided into two categories; objective and subjective. Objective burden refers to the observable negative occurrences, disruptions, or constraints that are directly related to the child's condition (Brannan & Heflinger, 2002; Montgomery, Gonyea, & Hooyman, 1985). Examples of these include the inability to participate in workforce and challenges associated with transportation, insurance, healthcare, or schooling that influence the caregiver and the caregiver's household. Subjective burden refers to the attitudes, feelings, and perceptions of the caregiver, which are related to the caregiving experience (Brannan & Heflinger, 2002; Montgomery et al., 1985). These may include guilt, depression, anxiety, or stigma.

Benefits Derived from Caregiving. Benefits derived from caregiving to a technologically-dependent child with severe disabilities are not well represented in the literature; therefore, this section will be dedicated to understanding and explaining this phenomenon in relation to understanding the holistic psychological toll caregiving has on the caregiver. Research has found that even while discussing the hardships of having to care for a severely disabled child, caregivers still attempted to portray a positive picture of their child and situation (Glasscock, 2002; Resch et al., 2010). Some have postulated that completion of all the daily activities and technological sophistication needed on the part of the caregiver give them a sense of accomplishment (Montagnino & Mauricio, 2004).

Other studies found that parents reported a positive and lasting impact on the whole family from the disabled child and caring needs of that child. Also, caregivers disclosed that being able to rise to the occasion gave them a greater purpose in life, greater spirituality, increased compassion and tolerance for people with disabilities, increased mental and emotional strength, and a more unified home life (Murphy et al., 2006; Resch et al., 2010). Furthermore, Resch et al. (2010) found only socio-cultural factors contributed to burden, not the child or the care given towards that child. It was the lack of necessary environmental supports that precipitated caregiver stress including access to information and services, financial barriers to obtaining services, school and community inclusion, and family support, not the child or the care needed to support that child.

These observations suggest the duality of consequences faced by caregivers -- that only acknowledging the negative beliefs and occurrences within the population of caregivers is in itself a bias in research design and reporting. It appears that the positive and negative experiences are connected and inseparable, and separating these would diminish the true experience of caregiving to a child with a severe disability.

Significance and Public Health Implications. A recent review by Resch et al. (2010) found few qualitative studies that address caregiver well being; only four percent of qualitative studies investigated burden issues related to caregivers, and most of those were in international journals. As local resources are generally called upon to provide services, there is a need for studies conducted in more local and regional areas.

Additionally, Anderson et al. (2007) found that qualitative literature lacked articles on caregiving to children with severe disabilities, including the personal and financial costs. Montagnino and Mauricio (2004) note that by using only surveys, researchers create an incomplete understanding of socio-cultural and individual level factors related to caregivers of technologically-dependent children, an open-ended questionnaire would give more insight into this phenomenon that cannot be achieved through quantitative methods alone.

Canning, Harris, and Kelleher (1996) found that little attention has been given to understand caregiver burden associated with caring for children with disabilities. Rentick et al. (2006) suggested that there should be more studies that focus on parental burden and coping strategies specifically related to caregiving for a child with CP. The authors suggested that by understanding burden, one can understand the needs of the families and identify those at risk for adaptation problems. Additionally, they mentioned that parents change over time, just as children do and by acknowledging this occurrence, professionals can attend to the burdens as they too change.

Glasscock (2000) reported that he found no studies that examined the experience of being a mother of a child with CP. He noted that although the number of individuals with disabilities has increased, the number of studies on caregivers to children with CP has not, and that explanations for positive caregiving experiences are lacking among studies that look at in-home care for children with CP.

This project aims to fill in gaps which have been identified in the literature; specifically, the current study attends to the lack of qualitative phenomenological studies in domestic settings about caregivers of children with CP and their experiences.

Additionally, it aims to identify burdens faced by caregivers of children with disabilities, and provides insight into the positive aspects of caring for a child with disabilities. This study adds insight to the expression of objective and subjective burden and positive experiences associated with caregiving among these caregivers in the Mid-South of the United States.

Chapter 2

Methods

Study Background

Between 2001 and 2002, Drs. Satish Kedia and Mario Petersen collected data related to feeding and adherence perceptions among twenty-six caregivers to children with CP who have a G-tube in Memphis, TN and surrounding areas. The main aims of the initial project were to provide a descriptive study in which the PIs examined the perceptions of feeding and adherence with caregiver to children with CP and who have a G-tube. This was in response to the medical community, which noted a high level of non-adherence within this population of caregivers. Researchers recruited participants through the child's primary care physician at University of Tennessee Bowling Center, staff from the LeBonheur Children's Medical Center Feeding clinic, and the state of Tennessee early intervention specialists. After obtaining written consent, one of the members of the original research team conducted face-to-face, in-depth semi-structured interviews in the respondents' house. Inclusion criteria consisted of the following: the caregiver being a English speaker; an established primary informal caregiving relationship; the child living with the primary caregiver for at least a year or since discharge from a Newborn Intensive Care Unit for younger children; the child having a G-tube for at least a month at the time of the interview; and the child being medically stable. The interviews varied in length from one to two hours and were recorded and transcribed verbatim.

Qualitative Analysis

For this thesis, a secondary analysis of the above mentioned data was conducted. The original study used a semi-structured interview questionnaire, which was developed by the principal investigators (PIs) and piloted three times before finalizing for this study. A questionnaire was created because the PIs felt that no existing questionnaire could capture the qualitative aims of the project. More specifically, the PIs designed a non-experimental semi-structured questionnaire that included qualitative and quantitative items, as no existing questionnaire was found that encompassed qualitative aspects, which were sought by the project. The topics covered on the questionnaire were general demographic information on the caregiver and family, the mother's social and medical history, information about the oral feeding of the child, information about the tube feedings, caregiver health and illness perception, caregiver's mental health, support networks, and caregiver coping.

All interviews were transcribed, and a first level thematic analysis pertaining to burden within that data was completed and archived by one of the principle investigator, Dr. Kedia, and then reanalyzed for this thesis project. Each transcribed interview was read in its entirety twice, one time to familiarize the researcher with the interview, then again immediately afterwards to identify information on the respective subthemes. In addition, the interviews were frequently reviewed while the results were compiled. These thematically examined data were used as the basis for current content analyses and helped to highlight the concepts of burden. The current researcher read through the archived data to gain insight into the population and burden related issues.

A comprehensive literature search was conducted and served to give understanding and context to the data obtained in this particular study. In the first level of thematic interpretation, many burdens were found and used as a platform for exploring the background literature. The literature search yielded the terms and definitions for objective and subjective burden. The literature search and the current researcher's previous experiences with caregiving to a technologically-dependent child with CP served to introduce the concept of benefits as well as reinforced existing ideas about burdens within this population. To increase confidence in interpretation of data, the current study researcher, Crystal Ton, examined each of the 26 transcripts to recode and reorganize under the newly developed themes of burden and benefit.

During the reexamination of the transcriptions, it was found that the negative and positive constructs were assessed differently in the interview protocol. Therefore different approaches were used to extract information on the two themes and will be explained in detail below.

Thematic Analysis. The thematic analysis provided an ideal method of understanding this dataset. As this study aims to explore phenomenological questions and to gather and understand information about the feelings and experiences of caregivers to children with CP, the use of this type analysis was deemed pertinent, and allowed for a comprehensive picture of the events that occur within the lives of these caregivers.

In this type of analysis, themes are abstract constructs that link expressions found in texts and represent significant concepts that link portions of the interviews together (Morse & Field, 1995; Ryan & Bernard, 2003).

Themes come from both the data (i.e., an inductive approach), as well as the investigator's prior theoretical understanding of the phenomenon (i.e., a priori approach) (Ryan & Bernard, 2003).

The act of discovering themes is what grounded theorists refer to as "open coding" and what classic content analysts label "qualitative analysis" (Berelson, 1952) or "latent coding" (Shapiro & Markoff, 1997). In content analysis, topics are examined to identify primary categories, and then are combined to form a thorough view of the theme in the data (Morse & Field, 1995). This approach, most associated with inductive or latent coding, served to become the foundation of the methodology for understanding the themes of burdens and benefits (Bernard, 2002). Each transcript was read and themes emerged from this part of the methodology.

Once the inductive process was completed and themes emerged from the data, a content analysis or deductive approach was employed to understand the themes more completely (Bernard, 2002). This deductive approach serves to highlight the categories, constructs, and domains present in the data and help explain the relationship between aspects of burden and benefits. Each transcript was then reread to extract the more precise categories under each respective theme.

A matrix (see Appendix A) was also developed to examine the interactions among the categories of objective and subjective burden and positive associations, which allows a visually complete understanding of the experience of caregiving to a technologically-dependent child with CP (Bernard, 2002).

Latent Content Analysis: Objective Burden and Benefits. The questions that address objective burden and benefits associated with caregiving are open ended (See Appendix B: see sections A and F); therefore using a broader type of methodology is appropriate. In latent content analysis, passages or paragraphs of interviews are reviewed to identify and code the intent of the section. This allows for the overt intent of the participants to be coded in addition to the analysis of the underlying meaning. It is important to make sure the content is actually what the participant says and the meaning behind their words, which was the reason why this style was chosen.

The categories that resulted from the latent content analysis for objective burden were: the inability for the caregiver to work as she would have normally; total lack of caregiver's income; lack of appropriate sleep; transportation problems; healthcare issues; school problems; acquiring appropriate health insurance or healthcare procedure because of insurance constraints; lack of childcare; and a decline in caregiver health. One of the categories, healthcare issues, was divided into sub-categories: doctors, nurses, therapy service providers, respite workers, and medication problems.

The inductive approach using the latent content analysis was also used to collect information about the positive experiences from caregivers. This approach yielded the following categories: the caregiver felt that they were meant to have this particular child, which was divided into the caregiver either knew why they were meant to have the child or they did not know why; the ability to care for the child made the caregiver feel positive; the caregiver was simply blessed by the child's presence on earth; the caregiver felt that a higher power had chosen her because she could handle the situation; the child possesses an innate quality that projects positivity; people who do not have disabled

children cannot understand the positives gained from them and the experiences; the child's disability shaped the caregiver's future career goals; and the caregiver does not see any disability (the child only has a disability when being compared to another typical child). Many respondents offered positive accounts of their experiences with caregiving without being prompted by the interviewer. When this occurred, the quotes were noted and categorized with the previously listed positive findings.

Manifest Content Analysis: Subjective Burden. Closed-ended questions were asked about the subtheme of subjective burden (see Appendix A: section G). Therefore, to capture the understanding of subjective burden, a process called manifest content analysis was used. In this type of content analysis, the researcher surveys the interview for words, phrases, descriptions, and terms central to understanding the research question or in this case the subtheme of subjective burden (Morse & Field, 1995). Under this process, responses from the closed ended questions were tabulated to form the subjective burden categories within the data. The categories which emerged include worry/nervousness/anxiety, depressed moods, crying frequently, easily irritated, variations of stress causing agents, distrust of child with others, guilt by the caregiver, overwhelmed by situation, perception of social isolation, and perceived social stigma of child or the technology required to sustain the child. Worry/nervousness/anxiety, depressive symptoms, and feeling worn out were combined and renamed as the emotional distress category, as reported in the results. The stress category was divided into stress related to the care required because of the G-tube and the stress caused by an institution or social environment, such as a school or social services.

As mentioned, many of the answers to questions were yes and no, therefore most of the responses were tabulations of these answers. However, there was another category under the subjective sub-theme that was not a response to a closed ended question; the category of being overloaded by the whole caregiving situation. This was recorded if the respondent directly stated that they felt overloaded by their situation in the interview or if the researcher felt that there were enough negative affirmations from the previous categories to indicate an overloaded caregiver.

Chapter 3

Results

Participants Demographics

Twenty-six caregivers were interviewed for this study. The children and caregivers were the same ethnicity, except for one family. There were 18 African American and 8 European American caregivers. Of these, 21 were biological mothers, 3 were foster or adoptive mothers, and 2 were grandmothers. Fourteen caregivers were married, 10 were single, and 2 were separated or divorced. While 10 caregivers reported not being married, 7 reported that they had another adult present living in the house hold. Two caregivers reported that they lived with their child's father, and both men earned income. Two reported living with adult siblings: one with her sister and her two children and the other with her 30-year-old brother. The 3 other caregivers lived with other family members: one with a 20-year-old nephew, one with a nineteen year old son, and one with her parents. The mean education level of the caregivers was thirteen years. The annual mean household income was $28,316, ranging widely from $7,800 to $70,000; the highest income reported was in a foster family. Nineteen caregivers reported their religious affiliation as Baptist, 2 as Catholic, 1 as Church of God in Christ, 1 as Church of Christ, 1 as Jehovah's Witness, and 1 as non-denominational Christian. Most notably, of the 16 birth mothers who reported having an ultrasound, 13 reported having an ultrasound that was normal, and only 3 showed varying problems including hydrocephalus and a lack of amniotic fluid.

There were 15 female and 11 male children with CP in the study, and the mean age was 4 years and 8 months, with a range of 8 months to 16 years of age.

Ten children had been diagnosed with athetoid, 8 with spastic, 2 with ataxia, and 6 with mixed CP. Based on a physician rating on the Gross Motor Function classification system, children were placed in the following levels; Level II (n = 2), Level III (n = 2), Level IV (n = 5), and Level V (n = 17). This classification system measures a child with CP gross motor functions, such as the ability to sit, stand, or walk independently and as the level increase so too does the level of gross motor functioning impairment. There are age levels for this classification system, such as before second birthday, 2-4 years of age, and 4-6 years of age. A child at a level II may be able to sit on the floor but need help balancing. A child at level III children would be able to creep or crawl, but that would be there primarily means of mobility. A child at a level V would not be able to maintain neck and truck control and would have no means of independent mobility (www.msu.edu/~hieckel/GMFCS.pdf, 2012).

Each child had at least one or more co-morbid conditions. They included preterm birth (n = 15), seizures (n = 10), bronchopulmonary dysplasia (n = 5), genetic or chromosomal abnormality (n = 4), Mental retardation (n = 4), blind (n = 4), and hydrocephalus (n = 3). All had a G-tube placed for at least one month at the time of the interview. Eighteen had a G-tube placed to prevent aspiration or to address an abnormal sucking or feeding, and eight to improve nutrition. Five children had a trach in addition to their G-tube. Other disorders reported that were either risk factors, causes, or compounding variables to CP were hip dysplasia, meconium stained/expression at birth, grinding teeth, liver disease, viral meningitis, CMV, asthma, tracheotomies with ventilator use, and reflux.

Twenty of the caregivers reported that their children were being covered by public insurance, either TennCare, Tennessee's Medicare program, or Medicaid-SSI, and eight reported having private insurance. Two people reported being covered by both public and private insurance. Many of the caregivers also reported utilizing state-sponsored public services. One of them, Tennessee Early Intervention Services provides physical, occupational, and speech therapy services to high-risk children up to the age of three at no charge. Another program, Special Kids and Families provides partial day childcare for a disabled child until three years of age; however, the organization will not feed a child via G-tube. Finally, services from the Health department that cover durable medical equipment were also utilized.

Objective Burden

Income. Almost 70% of participants (n = 18) reported that they had work problems directly related to the child's disability. Thirteen caregivers of the 18 reported that they were not able to work as they otherwise would have if the child had not been disabled. Reasons given were based on Medicaid income restrictions, the time needed for more medical appointments and therapy sessions, and a lack of child care for disabled children. A respondent sheds light on the challenge to work normally while caring for a child who has Medicaid:

> That's was why, on the income, for her to get her Medicaid and her disability, we can only make so much money. And, it all has to fit together, and It's just…we have to watch everything we do. #10

This caregiver highlights the type of imposed financial demands on these caregivers in order to gain access to much needed 100% medical coverage.

The current monthly Medicaid income allowance for Tennessee for SSI recipients is $674 for one person and $1,011 for two people with a resource limit of $2000 for one person and $3,000 for two people (Social Security Income Requirements, 2011). No reports could be found that indicated the income allotments and restrictions during the data collection period; however it is unlikely they have changed much over ten years.

Caregivers are often their child's only full-time advocate, and they can only do so much in any other domain including working. The next participant explains the core difficulties when raising a disabled child and trying to work, "…Because it's hard to work full time and be a full-time caregiver, so right now it's like, I'm not able to work full-time. It makes a difference." #5

Five caregivers reported that they had completely lost their income due to the child's disability. Reasons varied from the stress of going back to work was emotionally overwhelming, a lack of finding qualified childcare, and the demands of the child's needs. Five participants reported that they could not find childcare for their children because of their disability, which prevented them from being able to work additional hours. This caregiver explains her reasons for not going back to work after her daughter was born, "I was stressed out about it {going back to work}, because we have therapy four days a week, and um, I just couldn't do it. It was just too much." #1. The demands of caring for the child created a situation where this caregiver could not have justified going back to work to the detriment of her child. She felt her child needed to go to therapy four times a week, and this was impossible to achieve with the caregiver working. All respondents reported out of pocket expenses related to the child's care, but it was unclear as to whether they impacted the family's finances in any major way.

Possible reasons for this include proximity to children's hospital and use of public insurance and services among most participants. Most people were within an hour drive of Lebonheur Children's Hospital. Caregivers who must drive and spend the night in order to get the care needed for the child reported much higher monthly expenditures and personal costs on the family (Szilagyi, 2003). Also, many of the children were still quite small, yet as the child grows they require more equipment and services that may not be provided by either type of insurance, such as handicap accessibility of the home and cars or care.

Sleep. About 40% of the respondents, eleven caregivers, reported a lack of sleep linked to the child's care. In this category, participants revealed that the use of overnight life support (e.g., ventilators, feeding machine, or apnea machines) interrupted their sleep. Again caregivers describe how objective and subjective burden are intertwined, such as stress, depression, or anxiety prevented them from sleeping properly. The two following quotes explains these occurrences,

> I work, and then I take care of her, and it's just the daily demands that everybody has on me. And, maybe I can't wind down at night, because I'm still, in my mind, I'm still thinking about what I need to be doing. Maybe I just can't relax. I don't sleep good. #10

This caregiver talks about how her mind is unable to wind down, thus creating a situation where even after the child is asleep, she cannot relax enough to sleep herself.

The next caregiver explains the difficulties involved with being responsible for life-saving equipment that runs all night, and how her fears and worries prevented her from sleeping.

> Uh, I'm kind of programmed now that when she's in discomfort I hear her. If she needs suctioning, I'll hear it. I'm like, programmed now, but at first, when I got her, I never slept. I never slept. I was just so scared she was going to die over in the night. Is that weird?...I was just so scared she was going to die…and I wasn't going to hear her. #11

Transportation Problems. Two caregivers reported having problems with transportation. The reasons included problems with the car seat not properly fitting one of the children who has hip dysplasia and not having transportation that accommodates a wheelchair bound child.

> {Caring for the child} hasn't kept me from doing what I need to do in the past, but it's sort of getting to that point, because she's getting bigger. I, I usually take her to the store. I don't, you know, leave her at home. But it seems like now, she, she's been too big for the seat part of the {shopping cart}, and she's basically getting too big for the bigger part of the basket. So yes, it's, it's taking an effect. And, I drive a car, so there's no way I can just get her wheelchair in and out everything that I'm buying at the store in too. So, it's, it's getting quite difficult. #5

This caregiver talks about how difficult it is to travel with a wheelchair, and gather the necessary supplies in order to live. This individual explains how something as simple as going to the grocery store can become hugely difficult when caring for a severely disabled child. The participant becomes dependent on having someone to care for the child so that they can go to the grocery store, which reduces her ability to be self-sufficient and can create stress if no one is available to provide that temporary care for the child.

School Problems. After age 3, the school system is federally required to provide a disabled child's education and therapies. Therefore, until age 5, the school system can be the only fall back support mechanism for these families, if no daycare centers take physically disabled and technologically-dependent children.

At present, there is no daycare service that will take physically disabled children with technological-dependency in Memphis. Although educating a disabled child and providing appropriate services is a federal mandate, the decision of how many and what kind of services a child receives are determined by the therapist in conjunction with school resources. Also, the school system does not have to provide a full school day schedule and therapeutic services can be limited. In this study, caregivers were not consulted as to what types of therapy their child should receive in the school system

Many parents in the study reported that they had serious problems with the school system. An important note about the reporting frequency of school problems is that many parents had already dismissed the school system completely, and others did not fully participate in the system. For example, they would only send their child two out of the five days using their own discretion, or their child was not of the age to participate in the school system yet. Also, many of the children in the study were sick often and were frequently out of school, so their parents completely withdrew them from school.

Six caregivers exclusively reported concerns with the school system. Their responses included that the school did not care appropriately for the child, sanitation problems, schools refused to provide services, and a general sense of parental distrust with school.

> It was 12 O' clock…She suppose to be fed at ten. They called me at 12 o'clock and tell me my baby ain't ate. I said, Excuse me? They tell me, we can't feed her cause the doctor's orders not right. I said, okay, why didn't ya'll call me at eight o'clock this morning when she got off the bus? Or called me yesterday?....I went, I went over her {woman from Memphis city schools} when I got to that school, I say, is this the same way ya'll do a regular child…that's how I expect you to ya'll to do to mine! #4

This caregiver draws attention to the notion of a 'Medical Child'. Once a child becomes technologically-dependent, parents no longer have sovereignty over their child when it comes to the intervention. This means that when the intervention is a G-tube, the parents cannot just tell a system, such as school, when, how, and how much to feed their child. The child's doctor must write medical orders detailing the specific of the child's feeding. In this case, the doctor's orders were incorrectly written, and the caregiver was not notified in a timely manner. This is problematic as the participant indicates, and notes the inequality of this type of situation. It is likely that food would not be withheld from a typically developing child. This type of reliance on the medical establishment to guide instructional procedures for the child's nutritional care violated the rights of caregivers/parents.

Another caregiver explains her disdain with the school because of hygiene issues.

> They have a problem with the school being clean…She had a salmonella poisoning. She don't eat meat. So I wanted to know how she got salmonella poisoning, you know. But because I complained so much they kind of neglected {her}…. #11

This quote points to the dilemma where a caregiver must decide between educating her child or questioning her health and safety while at school. Parents are often left to wonder what goes on at their child's school because their child cannot talk and many are bused directly to the school from home, which reduces the parental oversight at the school. Parents rely on the assumption that everyone is taking proper health precautions, but sometimes that is not the case. Additionally, this caregiver believed that her child would be treated worse since she had complained so much about the child's environment.

Burden Created by Professionals. Almost 50% of the respondents reported objective burden created by the child's therapists, nurses, or doctors.

The most common themes within this category were doctors being insensitive to caregivers' feelings, doctors assuming that a parental interpretation of events was not medically sound, doctors dismissing parental concerns or wishes, or other professionals refusing to provide the care that parents requested.

> I took him to LOCAL HOSPITAL {because of dehydration}…Of course, they were staring at me like, 'Mom'. And, I'm like he didn't give me any signs {of dehydration}. I mean he quit eating yes, this morning. It wasn't like I hadn't done anything for two days; it'd been a very short time. And, then this supposedly lovely pulmonologist. I mean, he's a goddamned pediatric. Uh, if I hadn't been so tired and holding CHILD, who had so many tubes, that man would have flown out of the seventh floor window…Um, because he looked at me and said, 'You need a G-tube'. And, um, I said, 'well, he loves to eat'. And, I started crying, because when I get really tired I cry…there's so little he does get enjoyment of, I don't want to take it away from him…He said, 'Well, that's probably in your best interest then, 'cause uh, that way, next time he comes in then here…Well, he would, it would be a terminal type of thing, and it might even be in his interest if that happened'… #3

This child was admitted into a pediatric ER in Memphis, and when the parents were confronted with the reality that their child might need a permanent procedure, they became overwhelmed and immediately thought of their child losing one of his favorite pleasures in life, eating through his mouth. As she reported, the doctor insisted, and insinuated that it might be in the child's best interest if he die. She felt like the doctor took advantage of her being tired and run-down and imposed his beliefs on her that created an unnecessary emotional toll on her.

This phenomenon, unfortunately, was consistently reported by the caregivers; caregivers perceived that doctors projected their own opinions and assumptions of a situation without the sensitivity or acknowledgment of the caregivers' understanding of the situation.

> I told him that they looked like seizures. I told him at the beginning. He said he didn't think so. He'd never known for a little child of her age to have seizures. He thought it was reflux. So, he put her on reflux medicine at the beginning.

> And, uh, three weeks, maybe four, he had an EEG that showed him that it was seizures. So. And, then she got on medication. After the seizures were discovered by the medical community, and he put her on a high doses of Tegretol and Tagamet, reflux medicine, which ain't supposed to be given together because it will increase, the Tagemet increases her Tegretol…the effects of it…Tagamet not supposed to be given with it, that caused her delayedness…She was doing fine . She stopped all that once she got on all this medicine. He had her on about 10 different medicines at one time. He didn't want to refer her.
>
> I asked him many times, me and the father was there, to refer her to someone else. He didn't want to. He said he could handle it. He told me this out of his own mouth. #14

This caregiver knew that something was drastically wrong, but could not convince the doctor of such occurrences, and as a result her child continued to have seizures until the doctor had been sufficiently convinced. Not mentioned in the above quote, this caregiver had difficulties keeping her child away from surgery as a means to treat her daughter's seizures. Doctors wanted to surgically implant a device that might be able to control the seizures. However, the caregiver wanted to attempt a less invasive technique, a controlled diet, which has been shown to help hard-to-treat seizures. When she approached the doctors with this, no one wanted to support her. This is an example of when a caregiver asks for help with something that she wants to do with her child, and the medical community did not support her effort to exercise her autonomy over her child.

> Uh the speech therapist doubted it {that the child could swallow properly per a Swallow test}. Um because of CHILD's oral defensiveness…She gagged a lot. Um, she threw up a lot…I kept telling her that she was wrong. She could swallow just fine. She, she um her speech therapist and she do not get a long, so I had to intervene and start feeding her in therapy…You know because we feed her here, orally, orally…We use another {speech therapist}one now, and she eats quite well, so. #8

This caregiver stated that the child was being fed orally at home, and often a therapist will try to match what is occurring at home to increase a child consistency in therapy.

In this case, the caregiver wanted the therapist to work on increasing the child's oral feeding during the therapy sessions. The therapist did not agree with the caregiver's assessment of the child's abilities, which consequentially lead to acquisition of a new therapist, who did support the caregiver's wishes for her child in therapy.

> And so what happened was the nurses um, DOCTOR X used to be our doctor. And, we had so many problems with leaking {at the G-tube site}. I kept saying, the gagging…And, he said, 'it would get better. It'll get better.
>
> You need to try a little harder'. I'm like I'm trying to feed him. He is my third baby. If it was my first baby, you might could convince me I don't know what I'm doing, but I know how to feed a baby. And, this is not right… #6

Again, this caregiver experienced a doctor who did not take her concern seriously that something was wrong with her child's G-tube. The mother sought a second opinion, and the child received an appropriate tube replacement. Not attending to parental concerns appropriately adds an emotional burden to caregivers who are already burdened, and drains energy that should be directed to the care of the child.

> …When you're seeing the specialist referred to you by a doctor, it shouldn't take two months to get an appointment…We've waited, I called every day for two weeks until they had a cancellation…{you have to be aggressive} to the point of pushy and obnoxious, sometimes. #18

This caregiver's experience with the medical system evidences the frustration parents have when organizing the needed care of their child. This caregiver had to call a doctor's office everyday for two weeks in order to get an appointment/referral.

This caregiver further explained her perceptions about the doctors, "…The doctors don't do nothing. They don't do nothing but tell orders." #26. This mother held little faith in the ability of doctors in this case to help her with caring for her child.

Acquiring Appropriate Medical Insurance or Healthcare. Ten participants reported difficulties with gaining access to insurance and services in the private sector because of the child's disability or having to convince the insurance companies that they needed certain procedures or equipment. This often leads caregivers to report an increase in subjective burden. One caregiver said:

> Um, sometime I do {feel hopeless} …Especially when she can't get the things that she really needs, you know. That's the only time. But, I've been denied certain services because of the medical insurance that she has, 'Cause the insurance that she has, they don't allow her to have this or that. That's a hopeless feeling. #17

Additionally, this caregiver could not get the specialist her child needs because TennCare did not cover dermatological services. She also reported problems with a public insurance that required referrals, thus creating sense of hopelessness about her child's medical needs. Another caregiver talks about the fight to get her daughter the medical supplies she needs and the amount of energy required to deal with her daughter's Medicaid:

> Oh, well, they're a fight all the time. (Chuckling) You know, getting supplies and stuff like that. It's the government, you know, messing with the government…we've done pretty good with United Medical…We've been doing it long enough, and we stand our ground…And, so we have been fortunate to get the supplies that we need, except for the G-tubes. You know, it's a mess. So, it is such a hassle to do that. We just pay for it {the G-tubes}, you know. #12

This caregiver must spend her own money to purchase the G-tube for her child without a support from the medical insurance, which she indicates that should pay for that item. She indicates that the fight for services is sometimes not worth the energy required to get the equipment necessary for the child's survival.

Based on the above noted examples of objective burden, it is evident that caregivers often struggle in the areas of income, sleep, transportation, education, and healthcare.

A caregiver's ability to work is diminished and their sleep and self-care are interrupted. Adding to this, they find themselves having to battle with the healthcare, insurance, and educational systems with some regularity in order to protect their perception of their child's welfare.

Subjective Burden

Many of the objective and subjective burdens are intertwined. As noted by many of the previous quotes explaining the objective burden faced by caregivers, objective burden often creates or exacerbates subjective burden.

The categories that reflect this are: emotional distress, stress, stigma, social isolation, and feeling overwhelmed by their caregiving situation.

Emotional Distress. Emotional distress consists of worry, depression, or feeling worn out. Sixteen participants reported that they experience emotional distress related to the child's state of being or the care needed for the child. Almost all of the caregivers, who reported worry, anxiety, or nervousness, knew that they held those emotions, yet not all recognized them as problems. Some stated them as normal parts of their life and tried to cope through taking prescription medications, taking hot baths, exercising, or seeing a mental health therapist. Yet, a substantial number of participants reported overwhelming negative psychological impacts that were great and unchangeable. From their responses, it became clear that this population struggles with emotional distress due to their caregiving commitments and access to resources.

Worry. Worry kept caregivers up at night, prohibiting them from restful sleep. "I was just so scared she was going to die over in the night. Is that weird?...I was just so scared she was going to die…and I wasn't going to hear her." #11

This is an example of how the subjective burden, the fear and worry of her child's death, caused objective burden, the inability to sleep, in this caregiver.

> …Because I have to get up through the night and reposition her. I give 'cause she don't have no body sores or anything like that, so I get up through the night and she let me know, like, Mama, I'm ready to be turned over…Like I'm waiting to turn her over, she go on right back to sleep, sometimes I don't. So that's a yes and no, because I have to get up through the night…with her. #17

Additionally, this caregiver explains how the anxiety of needing to prevent bed sores, prevented her from sleep consistently through the night. She knew that her daughter needed to be repositioned in order to prevent body sores, and waiting on that responsibility prohibited her from finding restful sleep.

Worry was reported to be exacerbated by family members who question the caregiver's ability to take care of their child. Some participants reported that they had anxiety about the new things to come in their child's life and when the child is "out-of-her sight." Additional issues involved added worry or anxiety when the child is sick, which caregivers reported to be frequent.

Depression. Fifteen caregivers reported that they had depressed mood. Moreover, nine caregivers reported crying frequently, even during the interviews, and seven reported they get irritated easily. One caregiver explains the normalcy of sadness from her perspective, "Who don't get down in the dumps sometimes?" #19. She indicates that who would not get depressed sometimes when your caregiving role can be so diverse and infinite.

Other caregivers reported being dejected because of seeing other parents with 'healthy' children not appreciating what they have, "Sometime. And, I don't, this sounds mean, but when I see people with healthy children and they don't appreciate. It's kind of hard to tolerate sometimes." #22

Other caregivers felt depressed when trying to understand how such a great disability could happen to their child or to them. Biological mothers searched for reasons that could explain why this happened to their child, but rarely were answers found, which seemed to aggravate the situation. Self-blame and lack of explanations for why their child was disabled created depressive feelings in some caregivers.

> Oh yeah. I feel responsible 'cause I'm, you know, I carried because they may say what happened, but you know…but I do feel responsible, because I carried her and I be trying to wonder what I could have done to prevent it {her child's condition}. #2.

Worn out. The next category within this grouping is the caregiver reported that they were worn out by their responsibilities as a caregiver. Fourteen participants reported that they felt worn out by their experiences with caregiving, which was often coupled with the multiple effects of keeping everything else going in the household while caring for the disabled child. Some of the reasons reported by caregivers could be seen in the context of parenting a 'typical' child; however, the contextual effects of the technologically-dependent child's situation adds extra burden not faced by caregivers to typically developing children.

"Sometimes it really gets you down, and you get really tired. And you just kind of feel broken down, but she has this happy spirit about her, and she's happy all the time." #12. This last caregiver explains the paradox in which she lives. Her fight to keep her child alive wears on the caregiver. Some reported being tired and worn out, which contributed to feelings of depression. A caregiver reports that she "feel{s} broken down," yet still keeps fighting. This may allude to an explanation of how burdens and benefits can exist within the same experience of caregiving for some caregivers.

Stress. This category has two subthemes; the stress caused by the G-tube and the associated care needed, and the stress caused by institutions like school, social services, or the child's medical care network. The stress caused by the G-tube and the care needed for it is reported by over half of respondents (n=16). Some of the reasons were the difficulties in dealing with the complications of the tube such as infections at the G-tube site, leaking from the G-tube, or managing granulation tissue. Also, G-tube stress was associated with not being able to feed the child through the mouth anymore and taking away something that the child enjoyed, like eating different foods. Stress associated with complication of the G-tube is highlighted by the following quote:

> …(I): Tube leaking formula? (R): It leaked horribly…We leaked so bad that I used to, I got a car seat that he had to sit in beach towels to sit, I mean that's how bad it was…And we leaked {through} seven outfits a day, is what we went through. It was horrible! #6

Leaking from the G-tube site is commonly reported, and the severity that this caregiver experienced created excessive burden. The technology required to sustain the child can be cumbersome and necessitates a level of understanding and maintenance that is beyond that of typical parenting. Many of the problems with leaking can be remedied through either G-tube replacement or changing the type of tube, yet there is no perfect science of what works best for each child. Therefore, it can be a long process of trial and error.

Simply, taking away one of the pleasures the child enjoyed was enough to cause burden on the part of the caregiver, "I said you know he loves to eat by mouth…I'm not, I wasn't trying to, he enjoyed it." #3.

> Um, yeah, because to tell you the truth, I, I you know, it felt hard having a child that can't eat by mouth. She was already, you know, disabled. You know, I didn't want to make a baby not use her mouth…And they were telling me if she didn't, if she forgot how to use her tongue…they were saying that she wouldn't know how to do, talk, and I don't know, just hearing a lot of, you hear a lot of different stuff trying to make a decision. #2

The caregivers explain the difficulties involved in making a decision that would affect their child so greatly. Children who stop eating by mouth and receive a G-tube often times do not go back to eating by mouth later in life. “Cause they {the nurses} were telling me that a lot of babies with the tubes, they stop eating and they don’t want to eat, you know, and don’t want to use their mouth, and I said that horrible.” #4.
Many children become orally defensive, and will no longer allow objects into their mouth. Undoubtedly, this is a stressful decision to make for a caregiver.

The stress caused by an institution such as a school, social service, or the healthcare system is greatly coupled with the objective burden seen in the previous section. When systems created to help with a situation for the child fail to deliver, it causes added stress to the caregivers. Many of the reasons for stress caused by an institution were that the particular setting would not support the wishes of the parent, such as working with the child on oral feeding and not providing federally mandated services, such as speech, occupation, or physical therapy.

In the school system, a speech therapist is assigned to a child. However, the skill levels of speech therapists can range from technological support, such as working with augmented communication devices, to feeding support, to learning impairments, and speaking difficulties to name a few. Not all therapists focus in the same areas. The following caregiver indicated how this impacted her experience for caregiving when her daughter received a therapist that she did not feel was qualified to work with her child.

> She has a speech therapist out at her school, but she says, she really can’t help her because she works more with children who have like speech impediments and things like that….But she has no speech at all, and I don’t think they really know what to do…As she gets older and she’s a grown woman, it going to be very frustrating for her. #10

This caregiver faced a situation that created stress on her because the school/therapy system did not provide a therapist who had appropriate skills to provide services her child needed. Another caregiver highlights this occurrence as well.

> …And, they didn't want to give her speech {services/therapy} because you know of her circumstance…but she got a $900 Passey-Muir valve that they are not putting to use. So, I got a problem with that.
>
> That's a waste of taxpayer money, when you don't utilize the resources at hand…That's a problem. {The speech therapist} thinks it's a waste, and I tell him it's his job. #11

This was stressful for the participant and unnecessarily directed attention away from caring for the child, and is an example of how a social institution can create burden.

Stigma. One of the most notable categories was the parental perception of social stigma of a disabled persons or a stigma associated with the interventions needed to sustain the child's life. Seventy percent (n=18) of respondents felt some form of stigma associated with their child. Some caregivers had children who were very young, and they did not report as much stigma associated with their child. It is, however, likely that as the child ages the perception of stigma grows, due to the widening of the gap between typical and disabled children.

Types of stigma included people avoiding eye contact or staring at the child or the child's wheelchair, G-tube, or trach tube. Some caregivers stated that family members were scared of the child because they thought the child would die in their presence if they were babysitting or were fearful of the interventions needed to sustain the child, such as feeding through the G-tube. Also, some stated that they believed the family member was fearful because they thought they would hurt the child if they held them or tried to interact with them. While stigma from family and friends was troublesome, more notable stigma was reported from the general public.

Some caregivers said that they did not want to feed their child in public because of stares, "{Tube Feeding} is not something you want to do out in public, because people gawk." #6. Others would feed their child in the bathroom so that people would not stare at them during a feeding or would ask people around them if it was 'okay' that they feed their child via a G-tube, "Well usually, I don't feed her out in public. But there have been times where we've gone out to dinner…But, I'll ask if I'm somewhere, I'll ask 'Is it going to bother you {someone sitting by the family}, because I need to feed her." #5. The following quotes show how the public can create undue burden on already taxed caregivers.

> Um, yeah, but I think some people {are afraid to hold her}, friends you know, won't ask to hold her because they're not sure, you know, and they'll, I mean…But a lot of the public wants to know, 'she sound congested,' you know, 'What's wrong with her?' they're nosy. #1 [This same caregiver refuses to use the wheelchair in public to avoid stares.]

> Only when people say, 'Oh, I'm sorry' {about the child and family's situation}. And I go, 'what are you sorry about?' I, I try so much to bestow unto people, I don't know if I'm ever going to talk to you again about this, if you're going to feel sorry for me. #3

Social Isolation. Fifteen people felt that they were, or had been, socially isolated at some point in their caregiving experience. Social isolation was categorized by a response to a question asked in interviewers. Some respondents explained why they felt socially isolated and others offered insight as to why they no longer feel socially isolated. A caregiver below explains how the nature of the child's disability limited the time away from the house, which served to isolate her.

> Um, in the beginning, {child's name}, could not get out of the house. I remember…I respected my pediatrician. She said, 'Don't go to the mall. Don't go anywhere'. You know, we went to the doctor and came straight home. And, that I felt isolated at that point. #6

Within this group of caregivers, respite care is critical for the caregiver mental health.

The next quotes describe how the caregivers experienced social isolation and what impact respite care had on them, “No, not any more {does she feel socially isolated}. We, we’ve got um, respite nurses, and so...” #10.

> …You’re tired, you’re really kind of tied down. You’re limited what you can do and where you go. Uh, it was stressful; it’s not as stressful right now, because we haven’t been through a sick period for the last few months. But up until a few months ago, it was stressful…Aaaah, and I would be hollering, ‘I need some respite. I need some respite! #9

The following caregiver explains how having a limited amount of people over to her house makes her feel disconnected with community and perpetuates the feelings of isolation. She also continues to explain that it is hard for her to talk with her family, even though they are the only people who visit her.

> …We basically stay at home a lot…Basically, the only people that really comes to my house is my sisters, and my parents, and their children. That’s it…It’s really hard to talk to my family about my situation, and so uh, I have a church member that I talk to sometimes, but I basically just seek advice from the Lord, and He gives me answers, so I do that. #17

The following quote explains that finding people to watch the child is difficult, and often prohibits parents from getting out of the house, “Like yesterday was our anniversary, and we were stuck here, ‘cause you know, it’s you have to really know someone and trust them and know that they know what to do, just in case something happens to her.” #22. This occurrence creates a feeling of social isolation for the caregiver and family, which is also compounded by the unavailability of trustworthy people to help in the child’s care.

Another caregiver tells of how any time spent away from the house is spent at work, “I’m kind of in my own world. I don’t have, you know, I mean, I have friends, but I don’t have…I’m pretty much here or work.” #12. While she is able to spend time outside of the house, she still has no time to herself with other working adults.

This caregiver also reported that she sees a therapist and uses prescription drugs to alleviate symptoms of depression and anxiety.

Overwhelmed by Situation. Eleven caregivers felt completely overwhelmed by their caregiving situation. Age of the child may point to differences in feeling overwhelmed by the caregiving situation, as this caregiver explains, "I mean, cause she's totally dependent on me. She can't change her clothes, she can't use the restroom. She, she's just like a, a newborn, basically, just a bigger version." #7. This child was three.

> I don't have a life. I don't have a private life, like going with friends or anything because taking care of a baby with this problem is a full time job. You can't go out at night because you're worried if she's going to be fed on time, if she's being taken care of, or when she doesn't feel good and she's backing up the tube…It's just, it's a lot. #11

The quote indicates how the caregiving situation is much larger than a typical parenting role. When the child is 12-years-old and still in diapers or when the caregiver is worried that the child may not be treated right, the demands of this type of care can be overwhelming on the caregiver.

Benefits of Caregiving

There has been much evidence to suggest that caring for a child with CP and technological-dependency is laborious and adversely affects the caregivers. However, a less explored phenomena associated with this group of caregivers are the positive association or benefits perceived from caring for a child with severe physical disability. Two categories of the benefits associated with caregiving emerged from the data and are reported in this section; the positives gained from the experience of caregiving and the positives gained directly from the child.

Gains from the Caregiving Experiences. Under the first category of positive gains from the experience of caregiving, thirteen caregivers felt that they were 'meant' or chosen to have this particular child. Among these, seven felt as if they had a reason, while six did not. The following quotes highlight why people felt like they were meant to have their child, "And I was like, okay, God's sending me somebody to watch over me, you know, that's going to be there with me through the bad times, the good times, and we're going to be there together." #4. For this caregiver, the child represented a solace and fortitude, and this was something that the caregiver felt was provided by a higher power.

> Oh, yes {she has changed my life}. And for the better too. And, a lot of people have given us compliments about the way that we've handled this, but it's the same way that anybody would. It's your child, regardless, and you're going to make the best of it, and I don't know. I just, I don't dwell on the way that it is. I wish that she could do more, and that she could grow up to have a normal life, and you know, and do things that others do, but I don't dwell on that. I just accept the way she is, and we just take it one day at a time. But she has, and a lot of people couldn't understand that, she has made our life a lot better, even though she is like she is, we're closer. My husband and I have a better marriage, I think because you have to depend on each other you know. A bad marriage couldn't handle a child like this. (Chuckling) Seriously, you, you couldn't. #10

The act of being complimented on the way this caregiver cared for and parented their child provided them with a sense of pride and self-worth, and acknowledges caring for a child is what most parents do regardless of the disability or ability, perhaps normalizing her caregiving endeavor. She also points out that people do not understand how the child or her disability actually improved her life, and grew her relationship with her husband. The following caregiver indicates that the child is on earth for a reason, but can't explain why.

> Yeah, I would say she's here for a reason. Most definitely. I mean, because premature birth is just your body trying to reject the pregnancy instead of miscarrying. It's premature. I would say, she was meant to be here…Umm, I don't know what the reason is, I can't explain why… #5

Five caregivers indicated that doing what is needed for the child gave them a sense of self-worth, accomplishment, or achievement. The next quote is an example of this notion:

> I figure it's a good thing, you know, it brought me back to perspective, 'cause I was a swingin' single'. (Chuckle) All I did was go to work, go out, hang out…It, it really changed my life around. Um, in the past I was a single parent. My baby was nineteen years old. Uh, a lot of days I didn't come home from work; I hung out and everything. I really feel like this was a blessing that I, I got this experiences. I wouldn't never have no other way , if that other had gotten better, and wanted to get him, she could get the little boy, but not {the child with CP}. #11- Grandmother

Seven participants felt like a higher power had given them this particular child because they could handle the situation better than someone else. The following quote explains this from the perceptive of the caregiver.

> I think it happened for a reason. And, I think that, you know, for a long time I was like, why did it? We, we tried for like four years to have a child, and I had endometriosis, and I couldn't have one. And, I got treated for it and I got pregnant, and you know, I thought that the medicine caused all of this, you know. Cause I got pregnant right after. And, I though, there was never any complication on either side of the family. Nobody had anything wrong, you know or anything. And, it was like why did this happen to us…to our child? And, people always said, 'you know, well, God give kids to people that he knows will take care of them. And just, you know, feel special, feel lucky. And, I do. #12

Gains Directly from the Child. In the second category of positive gains directly from the child, eight caregivers felt that the child inherently possessed a positive quality, such as love, happiness, or blissfulness. The following quotes reflect how the child's spirit encourages and gives to the caregiver, "And you just kind of feel broken down, but she has this happy spirit about her, and she's happy all the time." #12. "Binkie-winkie has got a lot of love" #2.

Another participant suggests that their child has an almost spiritual quality that gives her a sense of benefit from being around her. “And I can see through the years, there are people that are so cold-hearted that have no caring for anybody, that can get around CHILD and you just fall in love with her.” #12. Some caregivers understood and appreciated life differently because of the child’s presence, “And, uh, she has helped me to uh, like I said experience a different side of life.” #14

Two caregivers reported that the child changed their career paths and helped to shape their future career decisions. This caregiver actively sought learning from and teaching by the child. She felt like the child, “I think she is preparing me, you know, for up the road. I want to work in a field with children. I feel I want to work with special people, you know.” #14. The next caregiver also knew that she was meant to have this child, because the child was meant to show her path in life altruistically and in her career, “I know I was {meant to have him}. He showed, I was shown my career and my calling is to care for sick. I’m going to nursing school…doing respiratory first. And, then I’m going to go to nursing school, because he showed me what I was good at. #13

Three people reported that their child was not supposed to live and just their presence on earth gave them a positive feeling, “Then you have to really say you’re blessed, ‘cause I’ve seen cancer patients, I have seen them…She’s here, she’s breathing, so.” #2 and “CHILD was not expected to live, but he’s doing fine now.” #13.

Chapter 4

Discussion

Interests in gaining insight into the experiences of caregiving to severely disabled children are fairly recent. Exploring and categorizing burden and benefits as experienced by caregivers of technologically-dependent children with CP is a challenge, because reaching these caregivers can be difficult; their time is concerned with the needs of their child, and research is not necessarily focused on this population's experiences. Through this study's use of the qualitative analysis, many categories and subcategories of burden have been identified that allude to environmental, social, and structural challenges, as well as the benefits, experienced by these caregivers. Each theme discovered in the data profoundly affects these caregivers and helps explain their experiences to the rest of the world.

Findings from this study about caregiving burdens, which were similar to other studies were reduced or eliminated income due to providing care to the child; problems with the school system, medical establishment, and insurance companies; emotional distress, social isolation, stigma, and feeling of being completely overwhelmed (Anderson et al., 2007; Brehaut et al., 2009; Glasscock, 2000; Kuster & Badr, 2006; Leonard et al., 1992; Manuel et al., 2003; Montagnino & Mauricio, 2004; Murphy et al., 2006; Spalding & Mckeever, 1998; Rentinck et al., 2006; Resch et al., 2010).

Furthermore, themes associated with objective burden, which complement existing literature, are the lack of ability of the caregiver to work either in a limited capacity or complete loss of income and insurance problems.

Thyen, Kuhlthau, and Perrin (1999) conducted a study where they looked at 70 mothers of children assisted by technology and who were cared for at home. The comparison group consisted of 58 mothers with children who had an acute illness hospitalization stay. They found that 37.1% of mothers in the study group were employed vs. 69% in the comparison group. Additionally, in the study group 32.9% of mothers reported that they quit their job to care for their child and 46% stated that they worked fewer hours after their child was diagnosed.

While there was no comparison group for the current study, many respondents, 70%, reported that they could not work as they wanted to due directly to their child's condition. Approximately 20% of caregivers reported a total loss of income due to the child's needs and care, and 50% reported a reduced amount of time they could work due to the child's conditions. These findings indicate that burden among these caregivers places a family at a financial disadvantage in contrast to families with typically developing children. Additionally, these families could have additional expenses due to the child's condition. Having a technologically-dependent child in the home can greatly reduce the caregiver's and her family's ability to obtain financial stability.

Many of the findings from the objective burden category in this current study give rise to questions not addressed in the literature, specifically how the school system prepare for caring for children with significant physical and cognitive impairments. The public school system is designed for typically developing children and is retro fitted to provide services for disabled children.

Simply having a federal mandate to educate a disabled child is not sufficient for adequately providing that supportive environment for the child. In many cases, the public school system cannot give the type of support caregivers need, such as afterschool, winter, and summer break care. This is a structural issue that should be dealt with on local and state levels to best tailor resources to needs of the families and students within the school districts. At the state level there needs to be an awareness that at least every five years there need to be an updated roster of school services available within the state and population surveys to understand where the needs are and what barriers exist to getting the needs to the population at risk.

Additionally, improper care during the school day created burden for many caregivers in this study and was related to emotional distress and the decision to keep children at home, thereby reducing the ability to earn income and have respite time away from the child. The philosophy of the school system is essential in providing the best services for the child and the caregiver alike. School systems that do not provide before and after school care as well as full day summer programs make caring for a disabled child much more difficult. The general lack of competition in the private and public sectors of schooling limits the availability and quality of services delivered to this population, which also contributes to a gap in services for this population. This again is a policy issue; there should either be a reward system for schools that do provide actual needed services year round to families with disabled children or there should be a federal mandate that requires school system to provide before and after and care year round. This would not only support the family, but increases the continuity of education and care for these children.

Many parents in this study have explained how there is little communication between them and the school system and this break down of communication caused burden. There should be policies in place that require teachers to communicate with parents of non-verbal children at least on a weekly basis, and ideally everyday via a notation. If these are not in place, parents are left to wonder whether their children had a good day, acted differently in school today, got their G-tube feeding on time or it was delayed for some reason, had a bowel movement today at school- this can be a significant issue for children with CP as constipation can be pervasive and difficult to treat-, and simply what the child did at school today. These are a few of the many questions that the child cannot answer for themselves. Moreover, many children with CP take the bus to their school, because families do not have the means to transport them and their wheelchairs to school. The busing issue compounds the teacher-caregiver communication issues because most caregivers do not see their child in the school environments on a regular basis, and therefore cannot ask the teachers and teacher's aides directly how the child's day was. This causes limited parental oversight of the child's environment. Better communication and parental investment and oversight should be reflected in school policies in order to reduce burden and strengthen the child's school experience.

The last objective burden category absent in other studies was the lack of sleep because of the child's disability. Eleven caregivers reported that they did not sleep appropriately due to the child's disability, and this hampered their ability to feel rested and have enough energy throughout the day. This category was also heavily tied to the creation or exacerbation of subjective burden.

From a public health perspective, acknowledging that caregiving places an individual at risk for insomnia, mental, and physical health problems can help health care providers engage in primary, secondary, and tertiary prevention efforts. Health fairs and other opportunities could provide a means of early problem identification and referral for intervention when appropriate.

The age of the child may play an important role in the understanding of burden, especially objective burden. This may be true due to the development and growth of a physically disabled child. Challenges associated with issues like transportation, insurance, and school are all likely to worsen as the child grows. Many of the respondents had young children, and this may give rise to future research that looks at regional longitudinal studies with a focus on exploring the transitional needs for families with severely disabled children.

Many of subjective burden categories are well represented in the literature, yet again many studies looked at one type of effect; like depression, anxiety, or stress; and rarely, did they offer a holistic picture of what subjective burden looks like to the caregiver.

The holistic picture of burden shows that many of the objective and subjective themes of burden were interrelated. When high levels of objective burdens are present, the respondent often reported experiencing subjective burdens. This reveals the importance of the socio-cultural environment in the prevention of burden in the caregiver. Caregivers reported the most amount of burden from poor social interactions and stress caused by the medical community, insurance, school system, and social services.

Interactions with these establishments seemingly produce the most amount of psychological distress. In order to better address concerns of the caregivers, these institutions, systems, and services should frequently reevaluate the needs of the populations that they attempt to serve and find gaps at the organizational/provider based level. This can be done through instituting mandatory two to five years community reviews of the needs of these populations and the services that are provided in their communities. Also, better insight should be given to how federal and state financial assistance is distributed through organization intended to help.

Eighteen people reported stigma associated with their disabled child being in public or getting the interventions needed to sustain life, such as G-tube feeding, wheelchair, or trachs. Fifteen people felt socially isolated and twelve people reported feeling both isolated and stigmatized. This signifies the pervasiveness of this phenomenon these caregivers experience. Social isolation is well represented in other research on caregivers of children who are severely physically disabled (Kuster & Badr, 2006; Yantzi et al., 2006). Out of the fifteen caregivers who indicated isolation in this current study, fourteen caregivers reported an additional psychological problem, such as worry, anxiety, nervousness, depressive symptoms, or were feeling worn out. Kuster and Badr (2006) found that social isolation was a significant predictor of maternal depression. It may be valuable for research to look beyond depression and focus on a broader picture of social isolation and the psychological effects of the caregiving. The impact of social isolation on the caregivers is not recognized in home and community care policies, such as not providing caregiver mental health or support groups. This indicates a need to revisit policies to better address caregiver mental health.

Additional examples of interrelated themes were anxiety about the child causing caregiver to experience sleeping difficulty. For example, a caregiver who could not find a childcare center properly equipped to care for her medically needy child questioned her ability to provide financially for her family, which caused stress. Another caregiver who was stuck at home most of the time with the child, because she cannot afford a handicap accessible van, explained how that removed for her community.

She indicated that she was socially isolated, which in turn effected her emotions and sleep. These types of child related occurrences coupled with environmental difficulties, such as with the medical establishment, school or insurance problems serve to describe a highly marginalized and disenfranchised group; a vulnerable population.

An interesting finding that appears to be unique to this study was the stress created by the G-tube or the requirements associated with the G-tube intervention. Sixteen caregivers reported some level of stress due to the care required to maintain the G-tube. The original researchers in this current study asked questions that attempted to examine adherence to G-tube feedings and medical advice. By allowing opportunities for caregivers to explain how they felt about the G-tube (e.g., its problems and weaknesses, how it made them feel, and how the G-tube changed the way they see feeding their child), this data may have identified a potential area of concern for this population not otherwise noted.

The present study offers a glimpse of some of the benefits gained by the respondents from their caregiving experiences. These caregivers have great affection for their children and often gain many positive benefits either from the experience of caregiving or directly from the child.

Twenty three out of the twenty six caregivers reported a positive gain from the experience of caregiving or simply knowing the child. Almost all caregivers reported some aspects of their experiences that were transcendent in nature and to which they felt thankful for having, such as: they were meant to have this child, the child held some power that was given by a higher power, or that the overall experience was so compellingly good that they would never think about another direction in life.

These benefits and rewards coupled with the burdens seemingly produce a contradictory internal process for the caregiver. However, it is argued here that it is a better description of the experiences of caregiving within this population. Exploring the complete picture of 'what it is like' to care for a child with severe disability and technological dependence is necessary in order to help alleviate the burdens and accentuate the benefits gained that almost all caregivers face. It seems that incorporating both positive and negative aspects of the caregiving experience has given a more complete picture to people outside of this enclave. Mothers in this study described their adaptations to the situation by stating "they never get used to the child's condition, but they get used to taking care of the child" and "the child's love is worth more than the tears and the fright" (378). In effect, the adaptation becomes the positive growth; therefore providing inoculation to some of negative aspects of caregiving. Understanding the positives associated with caregiving to children with CP adds to the understanding of experiences faced by these individuals (Glasscock, 2000; Montagnino & Mauricio, 2004; Resch et al., 2010).

Public Health Implications

Natural Care vs. Foster Care Setting. Resource distribution within the participants of the current study was noted to be uneven; specifically access to respite care and publicly funded insurance and social security income without income constraints. The most notable differences were between the natural vs. foster care setting. There is an existing disparity in access to resources among the natural, the birth mother or family, and foster caregivers in this study population. The foster care system provides support services for foster parents such as support groups, respite care, daycare- if applicable, Medicaid access regardless of income, and the child's SSI or other state derived income to help support the child (www.TN.gov, 2012). However, this is not the case with natural parents who receive no such supports to raise their own disabled children.

In the current study, the foster caregivers were the only participants to report participation in support groups and, overall, reported access to more services such as respite care and daycare. Each foster caregiver reported access to an income based service, such as SSI or Women, Infants, and Children (WIC) and Medicaid without being mandated to meet the income eligibility requirements. Just the child's presence in the foster care system gave them access to the resources. Some of these services alone could alleviate stress or worry for many of the natural caregivers. Among the birth mothers, eight reported that they would benefit from access to a support group. Two did note that providing childcare would be essential and condition specific support groups would be better than general support groups. Three noted that respite care would help if they had access to it. The support services available to foster parents make their experiences

categorically different from those experiences of natural caregivers. Similar resources should be made available to both types of caregivers whether the child resides in a natural or foster care setting.

Furthermore, the consideration of institutionalizing or placing a child in foster care is directly related to whether the family can afford to care for the child in the home (Jacobs & McDermott, 1989). The natural home vs. foster care inequalities should be eliminated so that biological or natural caregivers can access the same type of resources as the foster care families. The children are the same regardless of where they live and the same caregiving burdens occur in both types of homes and amongst all types of caregivers. The presence of such an inequality and the cost to society when the caregiver is not supported makes a convincing argument for providing financial and social support for family home caregivers to help eliminate unnecessary and expensive long term institutionalization or placement in the foster care system (Jacob & McDermott, 1989).

The Medical Child. The burden created by doctors and the medical professions was a main concern for many study participants and elicited some of the most dramatic responses. Adherence concerns are often addressed in literature and research, but the term adherence denotes a one-way relationship between the professional and caregiver; the doctor/professional gives advice that a patient should follow, which is based on a disease model of health and does not necessarily match with the patient's perspective of health (Helman, 2001). Yet, in this study something else emerged; the burden reported by this population with regards to the medical establishment was created directly from the professionals themselves, not necessarily the burden from treatment adherence. This unique burden brought about a notion of the Medical Child.

The definition that will be used for a Medical Child here means that when a child has such great medical problems, such as needing a G-tube and a trach, or physical and cognitive impairments, that the medical problems begins to overshadow the fact that the child is still a child, and does not exist within a vacuum but in a family unit. Additionally, when that child is placed into a system, such as the school system or medical establishment, it becomes assumed by those systems that the medical community knows more about the child than their caregivers, which is different than the typical child, whose parents are assumed to know what is best for the child. This is evidenced by the fact that parents cannot give feeding amounts and schedules directly to the school system, they must come from the doctors. A doctor's order must be faxed to a school system before the school will deliver liquid food through a child's g-tube. In many cases the parent is more capable of explaining the feeding schedule to the school than the child's doctor because of the daily interactions she has with her child. One caregiver noted that the school system did not receive her child's order for feeding from the doctor correctly, so the school withheld food from the child at school for a few days. She was not notified that this had occurred, and had no way of knowing this because the child is non-verbal. Additionally, a caregiver reported that she felt like her child was having seizures and the pediatrician disagreed and withheld appropriate treatment, only to find out later that the child was in fact having seizures. This type of disparity in power and limited parental autonomy can cause burden on the part of the caregiver and may be detrimental to the health of the child, as reported by multiple respondents of this study.

For the medical child, it is counter-intuitive that a doctor, who may see a child on a limited basis, knows more about that child than the caregiver.

Yet, the medical doctor and the caregiver are not seen as equals when addressing the needs and concerns of a Medical Child in certain socio-cultural environments. As outlined by several respondents in this study, this type of dismissal of the caregivers' abilities creates various types of burden on the caregiver. Health policy should reflect this phenomenon so that doctors and caregivers have more mutual interactions and can provide the best support and care for the child. Caregivers need to be understood as the first and most qualified advocate of their child, and doctors are there to provide support to the child and parent. Doctors are often given ample amounts of power with a Medical Child, yet have little to do with the day-to-day care and maintenance of the child. This is not to say that all doctors are trying to reduce the autonomy of caregivers, but at the legislative levels this notion should be known so that more appropriate polices can be established to reduce this type of burden on caregivers.

The Role of Public Health in Beginning-of-Life Caregiving. There is limited understanding about the phenomena of caregiving in the public health sector as it relates to beginning-of-life caregiving, such as caring for a child with a severe physical disability. It is important to distinguish the end-of-life caregiver from the beginning-of-life caregivers because the differences between the two groups largely determine their particular caregiving needs. For instance, a caregiver for an individual with Alzheimer's disease can have a much different experience of caregiving than a caregiver for a child with severe disability. The caregiver might be concerned about safety issues, diapering an adult, or driving. However, a caregiver to a handicapped child may be more concerned about social integration of the child, schooling concerns, and financial constraints. Furthermore, they are caring for a child who has had minimal life experiences.

Therefore, the child's quality of life is contingent on how much the caregiver can support and help develop a severely disabled child. Due to their sheer numbers, end-of-life caregivers get much more attention, which can be problematic from the perspectives of beginning-of-life caregivers as much of the relevant legislation and policy are shaped by the needs of end-of-life caregivers, with little attention paid to the particular differences in the two types of caregiving needs and experiences. More research should be carried out to better understand the experiences of caregivers to children with severe disabilities. As such, it may be beneficial if states adopt a state-wide surveillance system to monitor caregiver health, both physically and mentally, which could track differences in different groups of caregivers while tracking the problems and risk factors for health issues associated with caregiving. This could be done by mandating states to implement the caregiver module for the Behavioral Risk Factor Surveillance system, as described by the Rosalyn Carter Institute (2010). By doing this, researchers could uniformly analyze many groups of caregivers to understand their unique challenges and determine how their roles change overtime and how to eliminate known sources of burden.

Despite limited data available on this topic, it was evident that many of the caregivers in this study felt strong positive emotions associated with their child and the experience of caregiving. These ideas should not be overshadowed by the burdens they do face, but rather help to complement the true experience of caring for a severely physically disabled child. Identifying and understanding the positives associated with caring for a disabled child including the positive growth aspects and deeper understandings for life, can help design stronger and more effective public health interventions for caregivers to children with CP and who are technologically-dependent.

There is a need for outreach and public education on caregiver experiences. Much of the stigma and social isolation can be addressed by public awareness of caregiver concerns and needs, as well as outreach to those caregivers who feel socially isolated. This can best be addressed by public health programs that target the general public. Cultural sensitivity campaigns can also help with informing the general public. In addition, scientific grants and awards should be allocated for such endeavors. Mental health providers could utilize specially designed support services to access hard to reach caregivers. Researchers at the Veterans Affairs Medical Center in Memphis were part of an evidence based program called REACH (Resources for Enhancing Alzheimer's Caregivers Health) conducted in various places throughout the country. The program provides telephone support groups for caregivers to patients with dementia and Alzheimer's Disease (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). This model is inexpensive and easy to implement, and has been shown to provide support and higher quality of life for socially isolated caregivers. Caregivers for children with CP may also benefit from such a program.

As seen in the results section of the current study, caregivers experienced significant amount of stress caused by health professionals. Mandating evidence-based cultural sensitivity training that addresses common sources of caregiver stress for nurses, doctors, therapists, and respite care workers who frequently come into contact with caregivers could help diminish these burdens.

Medical professionals have a unique access to both the patient and the caregiver, particularly in a pediatric setting. The development, testing, and use of brief psychometric screens that can be easily used with caregivers could identify a caregiver who may be at higher risk for psychological distress. Many brief screening tools exist that attempt to measure and identify caregivers who are at higher risk of developing psychological problems, such as the one used to identify postpartum depression, but there needs to be a screening questionnaire that are specific to caregivers of severely disabled children. Some of the most observable phenomena that should be included in a brief screen for caregiver burden that these twenty six caregivers reported are sleep issues, mental health that is highly variable- meaning that crying frequently may be a part of caregiving within this population and may not necessarily reflect a problem, isolation, social stigma, and stress caused by the socio-cultural environments frequented by these caregivers. These issues are possibly specific to this type of caregivers and need to be taken into consideration when attempting to identity an overly burdened caregiver. Then, once a caregiver was identified, nurses, public health officials, or physicians could provide supportive services, attempt to petition the insurance companies for respite care, or refer the caregiver to a mental health provider.

Limitations

The researcher working on this thesis belongs to a similar caregiving population as the participants of this study, and as such has inherent knowledge of many of the situations described. While this is not necessarily a limitation, it is appropriate to disclose this as some subjectivity may be introduced in interpreting the results.

However, this researchers' background may have allowed for an enhanced understanding of the experiences study caregiver described. Additionally, the current study author was not a part of the original investigation, but did meet with and discuss with the Original PI on a regular basis. The study is qualitative in nature, which limited the current author's ability to make any generalizable statements about the findings and population, but provides very detailed explanations of the experiences of these caregivers in Memphis, TN.

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Appendix

A. Matrix

Objective Burden

Theme	Sub-theme (if applicable)	Participant Number
1. Inability for caregiver to work as normally would if child did not have disability		3, 4, 5, 6, 10, 12, 13, 17, 18, 21, 23, 26, 29
	1.A. Total loss of CG's income due to child's disability	1,2, 11, 22, 24
2. Lack of sleep because of child's disability		1, 9, 10, 11, 12, 13, 17, 18, 22, 26, 27
3. Transportation problems		2, 5
4. Healthcare problems		
	Issues with Doctors/Health Professionals	2, 3, 6, 8, 9, 11, 14, 17, 18, 24, 26, 28
	Medication Troubles	2, 28
5. Problems with School		2, 3, 11, 18, 24, 28
6. Difficulties acquiring appropriate Insurance or healthcare because of Insurance		2, 3, 6, 8, 12, 17, 19, 22, 24, 27
7. Lack of child care because of child's disability		4, 7, 14, 15, 26
8. Caregiver not taking care of self or decline in CG health because of child's needs		4, 11, 22, 29

Subjective Burden

Theme	Sub-theme (if applicable)	Participant Number
1. Worry/Nervousness/Anxiety		1, 3, 4, 7, 9, 10, 12, 13, 17, 19, 22, 23, 24, 26, 27, 28, 29
	Worn out	3, 4, 6, 9, 10, 12, 18, 19, 21, 22, 24, 26, 28, 29
Depressed Moods		3, 4, 5, 8, 12, 13, 17, 19, 21, 22, 24, 26, 27, 28, 29
Cries Frequently		4, 12, 17, 19, 21, 22, 26, 27
Easily Irritated		4, 13, 17, 18, 26, 27, 29

2. Stress…		
	Caused by care required by the G-tube or the child's sheer need of a G-tube	1, 3, 4, 5, 6, 7, 8, 13, 15, 17, 18, 19, 21, 24, 26, 29
	Caused by an institution...	
	School	2, 3, 10, 11, 18
	Social Service Branch	5, 6, 10, 24
	Medical Establishment	9, 1, 24
3. Distrust of others watching child		2, 9, 22, 28
4. Guilt of Child's Disability		2, 22, 28
5. Overloaded by Situation as a Whole		2, 3, 5, 6, 9, 10, 11, 12, 17, 27, 28
6. Perception of Social Isolation		3, 4, 6, 7, 9, 10, 11, 13, 17, 19, 22, 26, 27, 28
7. Social Stigma of child or interventions needed to sustain child		2, 4, 5, 6, 8, 9, 10, 11, 13, 14, 17, 19, 23, 24, 26, 27, 28, 29

Benefits

Theme	Sub-theme (if applicable)	participant number
1. CG was meant to have particular child		
	Knows why	4, 8, 10, 11, 15, 22, 26, 27, 29
	Does not know why	1, 5, 6, 9, 14, 24, 28
2. Ability to do what child needs makes her feel positive		2, 9, 14, 15, 23
3. CG is simply blessed by the child's presence (and not death)		2, 13, 17
4. G-d choose her because she could handle the situation		2, 9, 12, 15, 22, 27, 29
5. Child gives a beneficial emotion to those around him/her		2, 3, 5, 8, 12, 14, 18, 24
6. Child shaped CGs life		13, 14
7. Does not see their child with a disability		8, 17

B. Questionnaire

CONSENT FORM
SIGNED BY _____
CUSTODY OF CHILD _____
INTERVIEWER'S NAME _____
LOCATION OF THE INTERVIEW _____DATE _____TIME _____

A: DEMOGRAPHIC INFORMATION

1. Name of child with disability____Age _____Gender ____ ,Ethnicity_____
2. Child's medical diagnosis _____
3. Siblings (Names/age/gender)_____
4. Primary caregiver's name _____ age _____ethnicity _____
5. Caregiver's marital status:_____, Caregiver's Relationship to child: _____
6. Is caregiver living with partner _____or spouse? _____
7. Is partner/spouse the child's father _____, mother _____other_____?
8. How long have you and your partner/spouse been together?_____
9. Religious affiliation of primary caregiver _____ partner/spouse _____
10. Occupation of primary caregiver _____# of hours worked weekly _____#years of education_____
11. Occupation of partner/spouse ___ # of hours worked weekly __#years of education_
12. Housing: Own_____, Rent _____**,** Other _____
13. Child and caregiver live: alone _____, with partner _____, friends _____, family_____, other_____
14. Please list other persons living in home and their relationship to child: _____
15. Please estimate your annual household income_____
16. Estimate the cost of special equipment, diapers, and formula for your child with the disability _____
17. How much do insurance or other programs help with these special expenses _____
18. Does child receive help with wheelchair ___, OT ___, PT ___, ST___, Communication Aids_____?
19. How much do the special needs of your child impact your economic status? _____
20. Is your child covered under Tenncare ___, Medicaid ___, private insurance ____, other _____
21. What is your primary source of help with expenses?_____
22. Does child have his/her own room? _____, share_____, with? _____
23. Does your child attend school? _____ Special programs _____ # hours daily in school _____ grade _____
24. How does your child get to school? _____
25. Who sees child off in morning?_____
26. Who is there when child returns home?_____

B: MOTHER'S HISTORY:

1. Mother, please tell me about yourself: Did you have any health problems growing up? _____
2. Tell me about your home life as a child

   _____
3. Did you smoke, use drugs, or alcohol? _____, During pregnancy? If yes, what kind, and how much_____, Did you ever have a STD?
4. Did you have an ultrasound during pregnancy? _____, Did the ultrasound show any problems? _____
5. How did you feel about any problems found?

   _____
6. Would knowing about the child's disability have affected your decision to have the baby? _____
7. Can you tell me about the father's health history? _____

C: HEALTH HISTORY OF CHILD:

1. Child's current age____, Born full term ____, premature ____, if premature # of weeks_____
2. Child's birth order in family_____
3. Did child have any birth defects? _____
4. Was child hospitalized after birth? _____ How long?_____
   Why? _____
5. How was child fed after birth? _____
6. Did your child have surgery while still in the hospital? _____
7. Tell me about any other surgeries your child has had. _____
8. Who is child's primary care physician? _____
9. Are all the childhood immunizations up to date?_____
10. Does your child have any medically diagnosed developmental problems? _____ Speech problems _____, learning problems _____, other_____
11. Tell me what this diagnosis means to you. _____
12. Do any other family members have health or developmental problems? _____
13. Has child had a swallowing test? _____ Results _____ Feeding recommendations _____ Feeding tube recommendations _____
14. How do you feel about the results of the feeding test and recommendations?_____
15. How would you describe your child's general health and nutritional status? _____
16. Does your child have problems with colds or pneumonia? _____
17. If yes, estimate number of times yearly. _____
18. Has any respiratory problem required hospitalization? _____ If yes, when? _____ Did the #/severity of problems affect the recommendations for a feeding tube? _____ _____ If yes, have the respiratory problems decreased since the tube was placed? _____
19. Is your child on any medications? _____
20. Are there any problems with medications? _____

D: ORAL FEEDING: YES NO

1. If your child still receives oral feedings, describe types of food _____ amounts _____, consistency _____, special positioning _____, any problems with choking _____, gagging ____, coughing ___, vomiting ___ _____, colic _____
2. Who is trained to feed child at home? _____ Babysitter? __ School? _____
3. Does the child eat well at home? _____ School? _____
4. Tell me what a typical mealtime is like for your and your child. _

E. TUBE FEEDINGS:

1. Feeding tube type _____ Age 1st placed _____ Ages replaced_____
2. Reasons for any replacement _____
3. Has your child has Nessen surgery for reflux?___ Any current problems with reflux? _ vomiting? _____ constipation? _____Dumping syndrome? _____
4. Tell me what affect the feeding tube has had on your child's overall health. _____
5. Does your child have any problems with the tube site such skin breakdown around tube?___, Leaking formula _____, bleeding _____, infections _____, accidental removal _____, other_____
6. Type of formula _____ amount _____ any liquids through tube _____
7. Other foods through tube _____ Do you ever give "tastes" of other food? _____
8. Tell me how you feel about feeding your child through a gastrostomy tube._____
9. Please describe what a typical feeding experience is like for you and the child. _____
10. Tell me about your feelings when the doctor first recommended a feeding tube for your child._____
11. What kind of effect do you feel tube feeding will have on your child's future? _____

F: CAREGIVER HEALTH & ILLNESS PERCEPTION:

1. How do you think your child's disability affects "your" life? _____
2. Do you ever think other people or family avoid your child? _____
3. Do you think your doctor can help you handle your child's disability? _____
4. Have you ever wondered if you did something to cause the disability? _____
5. Have you ever wondered if you were "meant" to have "this" child?_____
6. Do you feel this child has a special purpose in your life? _____
7. Have you ever regretted the decision to allow feeding tube placement? _____
8. How do you feel other people react to the feeding tube? _____
9. Do you think it affects the way the child's body looks? _____

G: CAREGIVER'S MENTAL HEALTH:

1. Do you have difficulty sleeping? _____
2. Do you feel bad about your situation? _____

3. Do you have depressed moods? _____
4. Do you feel nervous? _____
5. Do you feel down in the dumps? _____
6. Do feel worn out? _____
7. Do you feel like crying? _____
8. Do you have poor appetite or over-eating? _____
9. Do you have low energy or fatigue? _____
10. Do you have low self-esteem? _____
11. Do you have a feeling of hopelessness? _____
12. Do you feel bad about your situation? _____
13. Do you feel responsible for your situation? _____
14. Do you feel anxious? _____
15. Is it difficult for you to control the worry? _____
16. Do you get restless? _____
17. Do you get easily irritated? _____
18. Do you get into arguments easily with others? _____
19. Do you frequently feel angry? _____
20. Do you frequently feel upset? _____

H: SUPPORT NETWORK/CAREGIVER COPING:

1. Do you feel socially isolated? _____
2. Who helps you the most with your child? _____
3. Do you argue with your significant other, friends, or family about your child's care or health issues? _____
4. Does your child's health keep you from providing care to your other children? _____
5. Does your child's health keep you from paying attention to your significant other? ___
6. Who do you turn to for support and advice? _____
7. How well do you feel your child's doctor answers your questions? _____
8. Do you understand what the doctor tells you about your child's condition? _____

I: SUPPORT NETWORK/CAREGIVER COPING:

9. Are you satisfied with your child's health care? _____

10. How much do you trust your doctor's advice? _____
11. How could your child's healthcare be improved? _____
12. How well do you think you cope with the stress of caring for a child with a disability? _____
13. Do you feel you get enough time for yourself to do the things you want to do? _____
14. Do you feel members of the health care team listen to your concerns? _____
15. Do members of the health care team value your opinions? _____

J: EXPLANATORY MODELS:

1. Why do you think this child was born with cerebral palsy?
2. How do you feel a child with cerebral palsy should be cared for?
3. What is the best way to treat cerebral palsy related feeding problems?
4. How do you plan to manage your child's problems in the future?
5. Who will you seek help from?
6. Do you attend any type of support group?

THE UNIVERSITY OF MEMPHIS

Institutional Review Board

To: Crystal Ton, Dr. Satish Kedia, and Dr. Mario Petersen Public Health

From: Chair, Institutional Review Board For the Protection of Human Subjects
irb@memphis.edu

Subject: Experiences of Caregivers with Children who have Cerebral Palsy
(110210-169)
Approval Date: December 1, 2010

This is to notify you of the board approval of the above referenced protocol. This project was reviewed in accordance with all applicable statuses and regulations as well as ethical principles.
Approval of this project is given with the following obligations:

1. At the end of one year from the approval date, an approved renewal must be in effect to continue the project. If approval is not obtained, the human consent form is no longer valid and accrual of new subjects must stop.
2. When the project is finished or terminated, the attached form must be completed and sent to the board.
3. No change may be made in the approved protocol without board approval, except where necessary to eliminate apparent immediate hazards or threats to subjects. Such changes must be reported promptly to the board to obtain approval.
4. The stamped, approved human subjects consent form must be used. Photocopies of the form may be made.

This approval expires one year from the date above, and must be renewed prior to that date if the study is ongoing.

Chair, Institutional Review Board
The University of Memphis

Cc: Dr. Satish Kedia